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ABSTRACT

The four issues of this newsletters are designed to promote the effective dissemination and utilization of disability research outcomes. The first two newsletters include parts 1 and 2 of "Disability, Diversity and Dissemination: A Review of the Literature on Topics Related to Increasing the Utilization of Rehabilitation Research Outcomes among Diverse Consumer Groups." Part 1 presents a discussion of the relationship of constructs such as race, ethnicity, culture, disability, and power. Influences within the rehabilitation system are presented, as well as descriptions of mainstream and ethnic cultures in the United States. Part 2 focuses on the characteristics of effective systems and how to build relationships within culturally competent organizations. The concepts about culture and diversity that were discussed in part 1 are related to issues in conducting research as well as issues in dissemination and utilization. Organizational, research, and dissemination and utilization recommendations are also presented. The third newsletter addresses disability research and the media, developing media relations, sharing research information with the disability media, publishing in journals, and publishing on the Internet. The last newsletter discusses the outcomes of a survey of how the National Center for the Dissemination of Disability Research grantees disseminate information. (Articles contain individual references.) (CR)

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THE

Research



Exchange

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Disability, Diversity and Dissemination: A Review of the Literature on Topics Related to Increasing the Utilization of Rehabilitation Research Outcomes among Diverse Consumer Groups

PART 1 — THEORETICAL FRAMEWORK

Introduction: Seeing and hearing "from a different position"

Linking disability research outcomes with the people who can use them is a complex task under any circumstance (NCDDR, 1997). The task is further complicated by, on the one hand, the enormous diversity in terms of broad demographic characteristics among people with disabilities and their families, and on the other hand, the relative homogeneity among rehabilitation researchers and service providers (Smart & Smart, 1997; Bradsher, 1995). Circumstance, race, culture, language, experience, and belief can influence people's access to information and services; their roles in and treatment by agencies and by other individuals; their goals for rehabilitation and independent living; and the kinds and sources of information they find to be credible and useful.

Communicating effectively—including both giving and receiving information, so that researchers and service providers clearly understand the needs and circumstances of those they seek to help, and so that consumers understand the uses, requirements, limitations, and benefits of research outcomes and rehabilitation services—is one of the most difficult elements in this equation. As the writer Hannah Arendt (1958, cited in Greene, 1993, p. 13) once observed, each person "sees or hears from a different position," and sometimes what individuals see and hear can diverge strongly.

Another way of considering this concern is to think of information as "culture specific." According to Cochrane and Atherton (1980, cited in Metoyer-Duran, 1991, p. 320) "the proper unit of analysis for considering information services in a culturally pluralistic society should be the 'cultural community,' which is composed of potential users who may have distinct values, beliefs, and attitudes towards external information services." Metoyer-Duran also quotes Menon's (1983) observation that, because information is culture specific it is, consequently,

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A WORD FROM THE DIRECTOR

D & U that Meets the Needs of Diverse Audiences

After years of effort and the substantial literature regarding dissemination and utilization, why do gaps remain between research and its use? The most frequently cited reason is the lack of communication and cooperation between researchers and their intended audiences (Leung, 1992). Researchers who do not know their audiences well may not understand their need and use for research results.

The ranks of under-represented groups in disability research include people with disabilities who are also members of racial, ethnic, or cultural minority groups. Frequently, dissemination strategies do not take into consideration the special factors that would enhance the utility of disability research to minority group target audience members. An understanding of the information and research needs of multicultural groups should be a basic, rather than peripheral, tenet of research and dissemination design.

Research results should be stated in user-friendly language, and provided in formats and modes of information that are accessible by targeted audiences. The NCDDR has received requests from a number of NIDRR grantees for help in identifying strategies to ensure that knowledge generated from NIDRR-funded research can be utilized more fully to improve the lives of all people with disabilities and their families.

The review of the literature presented in this and the following issue of *The Research Exchange* was prepared to help researchers better understand the interaction of disability, diversity and dissemination. The first part provides a theoretical framework examining the concepts of race, ethnicity, and culture, and their influences within the rehabilitation system. The second part (to be presented in Volume 4, Number 2) will describe the characteristics of effective 'culturally competent' systems, and the impact of attending to diversity in conducting research as well as in dissemination and utilization. A number of organizational, research, and D & U recommendations are suggested.

John D. Westbrook, Ph.D.
Director, NCDDR



Leung, P. (1992). Translation of knowledge into practice. In Walcott & Associates, *NIDRR National CRP Panel Final Report*. Washington, DC: Walcott & Associates.

Introduction: Seeing and hearing
"from a different position"

continued from page 1

"largely incommunicable unless it has been 'acculturated'" (p. 320). A major element in the dissemination and utilization process, then, is to find ways of "acculturating" information about rehabilitation research outcomes, a task that includes listening as well as speaking.

Such a task, in some ways at least, may sound deceptively simple: Gather information about a specific culture and tailor the resulting materials and media accordingly. However, there are a number of complicating factors, discussions of which will form the bulk of this literature review:

- Concepts of race, ethnicity, and culture are often intertwined and misapplied, and often in ways that result in stereotyped beliefs about groups and individuals.
- It is problematic to assume that minority groups share a common culture or other characteristics. Rather, it is important to look at subpopulations, seeking to identify commonalities and differences. As Bartolome and Macedo (1997) conclude, "We need to avoid the lumping of multiple identities into a monolithic entity such as race or ethnicity" (p. 224).

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- The concept of culture refers not only to groups of people who can be distinguished by a common geography, bloodline, language, and/or set of customs. One can also speak of what Mason (1994) describes as "non-ethnic cultural groups," including, for example, "lesbians and gays, elders, women, people with disabilities, religious minorities, and others" (p. 1).
- As Sonia Nieto observes, "culture is often thought of as a characteristic rather than a process" (Kenyatta & Tai, 1997b, p. 176). However, it is in reality fluid, constantly evolving.
- It is often difficult to sort out factors that are related to culture rather than to socio-economic status or other life circumstances.
- The issue of power—of institutionalized patterns of inequity that lead some groups to be subordinated to a dominant, "mainstream" group—is one of the greatest barriers to the development of a rehabilitation research and service system that is responsive to the needs of all people with disabilities. The volatility of this issue makes it extraordinarily difficult to examine and address.

Many reports addressing the topic of diversity consist primarily of lists and descriptions of characteristics that differentiate "minority" cultures from that of mainstream U.S. culture, and discussions of ways that researchers and rehabilitation professionals can become more sensitive to those differences. This review will address some of those descriptions. But a broader conceptual orientation is necessary in order to get to the most persistent barriers and misunderstandings.

As noted above, diversity is a broad concept. However, the rehabilitation-related literature on this topic is limited, particularly literature that is grounded in empirical research. Material that does exist focuses almost entirely on racial and ethnic groups rather than on "non-ethnic" cultural groups. The scope of this literature review, therefore, is largely restricted to discussions related to racial and ethnic diversity. Another limitation is the lack of systematic information about

the characteristics and processes of rehabilitation research environments. Where the rehabilitation literature does address diversity issues, the focus is almost exclusively on service delivery, primarily via rehabilitation counseling. There is a small but growing body of material regarding the implications of cultural diversity for research and knowledge utilization in more general contexts, but little or none of this work specifically addresses the rehabilitation field.

Given the restricted research base, it is difficult to draw firm conclusions about many aspects of disability, diversity, and the dissemination process. Where possible, however, this document attempts to incorporate relevant information from other disciplines, particularly the literature on minorities and public health services, and educational and sociological inquiries into relations between minority and majority groups. It also attempts to apply the available information to the process of linking rehabilitation research outcomes with potential users, suggesting implications for the activities of identifying research needs, designing and conducting research, disseminating research outcomes, and promoting the utilization of those outcomes among targeted users.

The scope of concern

Incidence of disability among minority populations.

Race and ethnicity are among the factors that have "the strongest association with disability" (Smart & Smart, 1997, p. 13). Bradsher (1995) notes that, whether one is considering the overall disability rate in the United States, rates for people ages 15-64 (i.e., what is often considered "working age"), or rates of severe disability, African Americans and American Indians consistently have the highest rates of disability. Drawing on data from 1991-1992, Bradsher reports the following statistics:

TABLE 1

Percent of Americans with a disability/severe disability
1991-1992, by racial/ethnic group

	African American	American Indian	White	Hispanic Origin	Asian/Pacific Islanders
Percent with a disability	20.0	21.9	19.7	15.3	9.9
Percent with a disability, ages 15-64	20.8	26.9	17.7	16.9	9.6
Percent with a severe disability	12.2	9.8	9.4	8.4	4.9
Percent with a severe disability, ages 15-64	12.7	11.7	7.4	9.1	4.5

Source: Bradsher, J.E. (1995). Disability among racial and ethnic groups. *Disability Statistics Abstract*, 10, 1-4.

Incidence of disability among minority populations. *continued*

Bradsher also reports that women in each of these racial/ethnic groups, except for American Indians, have a higher rate of disability than men. However, when considering persons of working age, "there are no significant differences observed between disability rates for men and women aged 15-64, overall or within any racial/ethnic group" (p. 2).

Walker and Brown (1996), analyzing data from the National Center for Health Statistics, found African Americans and Hispanic Americans to be over-represented in all disability categories, including chronic health conditions: physical, sensory, and language impairments; and nervous and mental disorders. Similarly Walker et al. (1996), using data from the 1990 Federal census, report that although African Americans represent only 12.1 percent of the total U.S. population, they represent 14 percent of all persons with disabilities in this country. Among African Americans who have a disability, 71.8 percent have a severe disability, as opposed to only 52 percent of white Americans with a disability. In addition, 78.2 percent of African Americans with disabilities are unemployed or not working, and 41 percent are at or below poverty-level income. Among Hispanic Americans with a disability, 67.8 percent have a severe disability, and 27 percent live at or below poverty-level income.

Smart and Smart (1997) observe that "most Asians and Pacific Islanders do not fit the disability or socioeconomic profile of other minorities" (p. 10). However, recent immigrants, including Hmong, Laotians, Vietnamese, and Cambodians, are exceptions; many of these are refugees and tend to be both poorer and less well educated than other Asians in the U.S. According to Leung (1996), "Asian Pacific Americans are the fastest growing population in the United States today, with the primary growth of the last decade due to immigration" (p. 2).

An examination of data on public health reveals similar disparities in risk rates between white and minority populations. For example, in announcing a new health initiative last year, the White House released the following statistics:

Infant mortality rates are twice as high for African Americans as for white Americans. African American men suffer from heart disease at nearly twice the rate of whites. African Americans are more likely to die from breast cancer and prostate cancer. Overall, cancer fatalities are disproportionately high among both Latinos and Blacks. And Hispanic rates for diabetes are twice the national average; Native American rates are three times the national average. . . Asian Americans suffer from Hepatitis B in greater numbers than other groups. Vietnamese women are five times as likely to have cervical cancer, Chinese Americans four to five times as likely to have liver cancer. (Brooks, 1998, p. 11)

It is likely that race or ethnicity is not the root cause for the higher incidence of disabilities and chronic or

life-threatening health problems among minority groups, but rather "is fundamentally a measure of exposure to health risks (LaVeist, 1996, p. 24). As Ficke (1992, quoted in Smart & Smart, 1997, p. 13) warns, "It is important to note that the issue of causality between. . . demographic factors and disability often cannot be determined at all from the data."

LaVeist (1996) concludes that "at the core of race-associated differences in health status are social and political factors" (p. 23). McNeil (1993, cited in Smart & Smart, 1997) found that, among adults aged 25 to 64, the incidence of severe disability was 22.8 percent among persons who did not complete high school, but among college graduates, the rate was only 3.2 percent. Smart and Smart report that "African Americans, Hispanics, and Native Americans are consistently found to lag behind the general U.S. population in the number of years of school completed. . . This is also true of some subgroups of Asians and Pacific Islanders" (p. 12). Similar statistics can be cited regarding income levels among minority populations. Education, income, and discrimination (which often results in disparities in employment, education, and income) may be more primary influences on disability than race or ethnicity per se.

Inequitable treatment of minority populations.

As the National Council on Disability noted in its report to the President and Congress (Wright & Leung, 1993), "Many minority persons with disabilities face discrimination on the basis of both minority status and disability" (p. 2). Considerable evidence exists that people with disabilities who are African American, Hispanic, American Indian, or Asian Pacific American do not have the same opportunities for assistance, employment, or income as their white counterparts. Findings from Section 21 of the 1992 Amendments to the 1973 Rehabilitation Act (quoted in Flowers, Edwards, & Pusch, 1996), conclude that:

Patterns of inequitable treatment of minorities have been documented in all major junctures of the vocational process. As compared to White-Americans, a larger percentage of African-American applicants to the vocational rehabilitation system are denied acceptance. Of the applicants accepted for service, a larger percentage of African-American cases are closed without being rehabilitated. Minorities are provided less training than their white counterparts. Consistently, less money is spent on minorities than on their white counterparts. (p. 22)

These findings are supported by a series of studies conducted by the Howard University Research and Training Center for Access to Rehabilitation and Economic Opportunity (Walker & Brown, 1996; Walker, et al., 1996). One study found that "white clients tended to have more money spent on their program services than did any other group" (Walker & Brown, p. 31). Santiago, Villarruel, and Leahy (1996) conclude that "rehabilitation in the United States can be a very selective process whereby only individuals identified as being most

likely to succeed are referred to, and participate in, services" (p. 11). Standards regarding who is "most likely to succeed" tend to be based on white, middle-class perspectives. For example, Locust and Lang (1996) describe an incident in which "an Indian man, dignified and proud of his long braids, was told that vocational rehabilitation services for him would not begin until he cut his hair" (p. 6). Smart and Smart (1992) describe a state rehabilitation program in which "Anglo clients are often asked if they would be willing to relocate in order to facilitate job placement, but Hispanic clients are routinely assumed to be unwilling to do so and, therefore, are not asked about the possibility of relocation" (p. 30).

LaVeist (1996) describes discriminatory treatment in medical care, noting that "several studies have demonstrated race differences in clinical diagnosis as well as race differences in the intensity of medical services provided for a similar diagnosis" (p. 26). Research on utilization of mental health services among minority populations reflects similar patterns of inequity. Ridley (1989, quoted in Leong, Wagner, & Tata, 1995; see also Mohr, 1998; and Yamashiro & Matsuoka, 1997) concludes:

Compared to White clients, ethnic minority clients are more likely to receive inaccurate diagnoses; be assigned to junior professionals, paraprofessionals, or nonprofessionals rather than senior professionals; receive low-cost, less preferred treatment consisting of minimal contact, medication, or custodial care rather than individual psychotherapy; be disproportionately represented in mental health facilities; show a much higher rate of premature termination; and have more unfavorable impressions regarding treatment. (pp. 417-418)

Leong, Wagner, and Tata (1995) further note that "African Americans are disproportionately hospitalized" even though "studies have found no racial differences in the prevalence of psychological disorders among African Americans." They conclude that "the misuse of hospitalization for African Americans is probably due to clinician bias and/or problems in misdiagnosis (e.g., African Americans are more likely to be misdiagnosed as experiencing schizophrenia)" (p. 418).

Minority populations—particularly African Americans and American Indians—also are underserved by the national network of independent living centers (ILCs) (Richards & Smith, 1992). In a survey of 32 independent living centers in six midwestern states (including Illinois and Michigan, states with substantial proportions of African Americans and other minority populations), Flowers, Edwards, and Pusch (1996) found that 58 percent reported having no plans or programs "focusing on outreach to culturally diverse consumers." Of those who did, only three ILCs stated that they "felt that their plans were effective" (p. 26). The centers reported serving more than 8,000 people in the preceding year. Of the approximately 4,600 for whom racial/ethnic demographic information was reported, 89 percent were listed as "Caucasian." African Americans, at seven percent, were the largest minority group served.

The ILC survey also found that fewer than 20 percent of the centers' administrative staff (which include clerical staff and office managers as well as executive and finance directors and other professionals) were identified as members of culturally diverse groups. Twenty-two percent of direct services staff were from "diverse cultural backgrounds," as were 12 percent of members of the centers' boards of directors.

In terms of employment, Leung (1993) reports:

The statistical data for Blacks with disabilities indicates that while they constitute 19% of all persons of working age with disabilities, they constitute just 8.6% of year round full-time workers with disabilities. Similarly, Bowe (1992) indicates that adults with disabilities of Hispanic origin constitute 7.5% of all persons of working age who have disabilities, yet they are just 5% of year round full-time workers with disabilities. . . James et al. (1993), utilizing data from the National Spinal Cord Injury Statistical Center, found that Black persons with SCI were less likely to be employed than their White counterparts. (p. 94)

Walker and Brown (1996) found that, in three of four major categories of disability, "African Americans had the highest proportion of persons who were not in the labor force. Hispanics were also hard hit by unemployment" (p. 30). The authors also found a "consistent tendency for minority persons across disability categories to be at the bottom of the economic ladder and for whites to be at the top" (p. 29). Seelman and Sweeney (1995), in discussing the fact that people with disabilities tend to have lower incomes than nondisabled people, observe that "White persons with disabilities are generally in the low income ranks (\$18,000), but not as destitute as Hispanics (\$12,000) or African Americans (\$8,000), whose family income levels fall below the poverty index reported in the latest census (\$12,091)" (p. 3).

Some studies indicate that collateral factors such as education and income may contribute to differential treatment. Santiago, Villanuel, and Leahy (1996) conducted a "pilot survey" of 124 disabled working-age Latino adults in 1990-91 and found that "respondents who were high school graduates had 4 times higher odds of receiving MRS (Michigan Rehabilitation Services) than respondents with less than high school degrees" (p. 15). Similarly, a study by the Howard University Research and Training Center found that "clients with higher education levels and more economic independence at program entry had higher weekly earnings at closure and had more services provided to them during the program" (Walker & Brown, 1996, p. 31). As noted earlier, it is important to keep in mind that minority populations, whether disabled or nondisabled, continue to face discrimination in both education and employment.

Although most of the data regarding the treatment of specific populations within the rehabilitation system focus on racial or ethnic minorities, there is some evidence that women suffer inequitable treatment as well. Westbrook, Legge, and Pennay (1995) conclude that:

Inequitable treatment of minority populations. *continued*

Compared to men with disabilities women are more likely to be stigmatized, have poor self concepts, be unmarried, condemned for having children, left by their partners following disablement and denied access to education, employment, and financial assistance. . . . Discrimination against women with disabilities is also apparent in health care. Research . . . has indicated that such women are less likely than men to receive rehabilitation. (p. 26)

The socially constructed nature of race, culture, and disability

Concepts of race, ethnicity, and culture.

At the core of this literature review is a consideration not only of the differences among people, but of the ideas humans construct about those differences, the ways in which those who fit most easily into the dominant culture of U.S. society tend to value and devalue certain differences, and the impact of the dominant cultural perspective on minorities with disabilities. Such a consideration must begin with an understanding that the very definitions of terms like culture, race, and disability are grounded in a particular time, place, and perspective. Rather than mirrors that precisely reflect reality, definitions of these terms and ideas about them are imperfect human constructs (Kenyatta & Tai, 1997a,b; Scheurich, 1993).

Defining culture. The term *culture* has been defined as "a learned system of meaning and behavior that is passed from one generation to the next" (Carter & Qureshi, 1995, p. 241), and as "all the customs, values, and traditions that are learned from one's environment" (Sue & Sue, 1990, cited in Sodowsky, Kwan, & Pannu, 1995, p. 132). According to Sodowsky et al. (1991, cited in Sodowsky, Kwan, & Pannu, 1995) in every culture there is a "set of people who have common and shared values; customs, habits, and rituals; systems of labeling, explanations, and evaluations; social rules of behavior; perceptions regarding human nature, natural phenomena, interpersonal relationships, time, and activity; symbols, art, and artifacts; and historical developments" (p. 132). Culture, then, acts as "a unifying influence. It combines the different aspects of life into a logical whole" (p. 132).

Cultures are constantly evolving in response to changes in the environment; as Venkatesh (1995, p. 30) notes, "no culture stands still." Moreover, because culture is a learned phenomenon, "individuals and groups can and do change their ethnic or cultural identities and interests through such processes as migration, conversion, and assimilation or through exposure to modifying influences" (Smedley, 1993, quoted in Carter & Qureshi, 1995, p. 241). In bicultural or

multicultural contexts, such as are prevalent in the United States, the interaction between cultures often acts as a modifying factor. Life events, psychological characteristics, and other factors also can mediate cultural influences.

Harry (1992) argues that the most important thing to understand about culture is that "standards of social behavior are culturally derived." She also observes that "the closer one is to one's original culture, the harder it is to recognize the culturally specific, rather than universal, base of accepted norms for behavior" (p. 57).

Defining "race" and "ethnicity." The concepts of race, ethnicity, and culture are sometimes used to describe the same things. Wright et al. (1983, quoted in Harry, p. 5) attempt to distinguish among these terms: "Ethnic groups will be so defined if they share a common sociohistory, have a sense of identity of themselves as a group, and have common geographical, religious, racial, and cultural roots. The central core of each ethnic group, welding it together with the thread of belief, styles of being, and adapting, is culture. . . . Race is, at this point, a dubious biological designation" (p. 13). Tatum (1997), in supporting this last point, notes that "race is a social construction. Despite myths to the contrary, biologists tell us that the only meaningful racial categorization is that of human" (p. 16).

A number of scholars in the fields of sociology and education discuss the particular function of the concept of race in the United States. Takaki (1993) points out that, in the U.S., race "has been a social construction that has historically set apart racial minorities from European immigrant groups" (quoted in Kenyatta & Tai, 1997a, p. vii). Harry (1992) observes that, in this country, "the use of the term *minority* essentially represents an attempt to categorize by race, not by culture. Yet the specifics of race are only important on one dimension: whether one is White or not" (p. 3). Analyzing the racial categories used by the Office for Civil Rights (OCR) and other institutions, she notes that:

the U.S. interpretation of White [is] as a pure, unmixed racial group, so that to be, for example, one-quarter Black is to be Black, while a person who is one-quarter White would also be Black. While Latin American and West Indian societies, which also share the history of slavery, have built into their view of race the fact of racial mixture, the U.S. interpretation reflects the enduring legacy of a much more oppressive form of the institution of slavery. (p. 47)

Harry analyzes "the political aspects of racial classification" (p. 5), observing that the OCR classifications mix geographic and racial features in ways that seem logically inconsistent but that support the conception of *white* as both racial and geographic (i.e., European):

The corollary "regardless of race" attached to the definition of Hispanic reflects the anomalous character of this group. The category Asian or Pacific Islander, for example, clearly includes a mixture of racial groups, yet the classification system does not specify "regardless of race" for this group, presumably because Whites are not likely to be among them. . . . It is not required, then, to distinguish between the dramatically different racial characteristics of people from India and China. . . . Nor does the category Black (not of Hispanic origin) reflect any more logic, since many Hispanics from Caribbean and Central American territories have origins in the Black racial groups of Africa. (p. 6)

The U.S. Office of Management and Budget (OMB), responding to concerns about racial classification, recently revised its standards for classifying federal data on race and ethnicity. The new standards set five categories for data on race, including (1) American Indian or Alaska Native, (2) Asian, (3) Black or African American, (4) Native Hawaiian or other Pacific Islander, and (5) White. A separate designation for data on ethnicity includes two categories: (1) Hispanic or Latino, and (2) not Hispanic or Latino. According to these standards, respondents are to be encouraged to select multiple racial categories where appropriate. In modifying the standards, OMB (1997) notes that:

The racial and ethnic categories set forth in the standards should not be interpreted as being primarily biological or genetic in reference. Race and ethnicity may be thought of in terms of social and cultural characteristics as well as ancestry. (p. 58782)

Several scholars note the increasing tendency to substitute *ethnicity* for *race*. Kenya & Tai (1997a) conclude, "Some researchers and educators use ethnicity interchangeably with race because, we believe, they are still uncomfortable with race, racism, and its role in education" (p. vii). Margaret Andersen, a panelist in a forum on education and ethnicity, also questions this exchange of terms:

The caution I would put forth. . . is that in abandoning the concept of race, there is a serious tendency to abandon discussions of power, domination, and group conflict. . . . I cannot help but notice in works on ethnicity how quickly the discussion there turns to matters of culture and identity, not at all to questions of economic exploitation, political power, and powerlessness. (Kenyatta & Tai, 1997b, p. 177)

The term *race* provides a good example of the difficulties in determining appropriate terminology to apply in describing particular groups. Some authors note that the word lacks meaning in terms of the physical or biological differences implied in its common usage, while others argue for the term's political and sociological importance. Perhaps the critical point

is the necessity to recognize and make explicit the purposes and assumptions that are bundled into the use—or avoidance—of such words.

Disability as a socially constructed concept.

Disability, like *race*, *ethnicity*, and *culture*, is a term whose definitions are culturally derived, even though its meaning in the U.S. has been given what Harry (1992, p. 113) calls "transcendent status." Luft (1995) observes that "disability categories are primarily defined according to middle-class developmental norms" (p. 3). The significance of such norms, she notes, "is in their impact on the procedures used by social institutions in providing services—procedures that tend to be predicated on the clients or recipients behaving according to cultural expectations and standards" (p. 9). Harry concurs; in discussing the concept of disability inherent in the Education for All Handicapped Children and other federal law, she states:

Professionals interpret the model [of disability] inherent in the law as actually transcending culture. They come to believe that the definitions of disability deriving from the technological culture of the United States in fact represent universal truths. (p. 237)

Harry concludes that one reason for the assumed universality of ideas about disability contained in U.S. law, policy, and procedures is "its base in the highly esteemed science of medicine." This same esteem leads to the assumption that experts "hold the keys to truths regarding the conditions and needs" of children with disabilities (p. 113)—an assumption that often devalues the perceptions and understandings of the individual, family, and community.

Harry, Luft, and other scholars are not attempting to argue that disabilities do not exist, or even that all responsibility for individual limitations rests with the external environment. However, they do observe that the conditions included in the term *disability* vary in different contexts, and that diagnosis of specific conditions is often subjective and culturally derived, as are judgments about the severity, impact, and appropriate response to those conditions. As Smart and Smart (1997) conclude, "Disability is not caused by disease and injury alone, but is also related to the way in which institutions define and diagnose disability" (p. 12). The following examples illustrate their point:

- Smart and Smart (1997) note that "there is no uniform definition of disability since government agencies define disability differently. . . . Further clouding the picture, some health demographers do not define disability as completely as do rehabilitation demographers," excluding for example, conditions such as alcohol abuse and learning disabilities (p. 10). The authors also cite a 1993 study which found that "in Alaska, only 3% of all special education students were classified as retarded, yet, in Alabama, 23% were considered retarded" (p. 12).
- "The arbitrary nature of the term mental retardation was dramatically demonstrated by the American Association on

Disability as a socially constructed concept. *continued*

Mental Deficiency (AAMD), in its radical revision of the definition from an IQ cutoff point of 85 to a mere 70. Overnight, the population of mentally retarded persons was cut by 13 percent" (Harry, 1992, p. 144).

- "Between the years 1978 to 1990 the category of Learning Disabilities grew dramatically, Emotional Disturbance increased slightly, and numbers of children with Speech and Language Impairments, Hearing Impairments, and Mental Retardation gradually decreased" (Luft, 1995, p. 11).
- Shacht (1997), reporting case history information collected by the American Indian Rehabilitation Research and Training Center regarding American Indian consumers from five states, could not account for the following differences: "The distribution of *Reported Disabilities* varied in unexpected ways [among the 121 cases]: arthritis and rheumatism, and Alzheimer's disease were reported mainly from South Dakota; learning disabilities and emotional/mental disorders were reported mainly from California; various orthopedic disorders and diabetes mellitus [were] reported mainly from Texas; and paraplegia was reported mainly in Arizona" (p. 10).

The ways in which individuals, families and cultures perceive and accommodate disabilities also vary significantly. For example, in their study of young Latino men with disabilities, Santiago, Villarruel, and Leahy (1996) report that "only 37 percent of the 124 respondents in this investigation viewed themselves as having a severe disabling condition. Yet, when the information from the MRS screener was reviewed, 56 percent of these persons were considered to have a severe disabling condition" (p. 16). Schensul (1992), in a study of Alzheimer's disease among elderly Puerto Ricans in the U.S., notes that "elderly Puerto Ricans are aware of the symptoms of cognitive loss and behavioral change [associated with Alzheimer's disease] but tend to view them as normal" (p. 26). And Locust (1988, cited in Harry, 1992, p. 81) "points out that the prevalence of a congenital hip deformity observed among the Navajo is not considered disabling, while surgery to correct it may create a disability because it tends to make riding a horse uncomfortable."

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Cultural power and the perpetuation of inequity

Systems of advantage and disadvantage. The common assumptions in U.S. society regarding race, culture, and disability take on greater importance when the issue of power is added to the equation. The idea that one group is dominant while others are subordinate, that "systematic advantage and disadvantage" (Tatum, 1997, p. 9) are prevalent in the

United States, is not only abhorrent to most Americans; to many individuals, it may seem unbelievable. Based on individual experiences, some people may believe that disparities are real across one dimension, such as disability, but not across others, such as race or social/economic class. However, it is a basic sociological principle that societies stratify their members in terms of "power, resources, and status" (Pilisuk, McAllister, & Rothman, 1996, p. 16). An increasing number of scholars and researchers—including sociologists employing "network-analytic" research methods (Stanton-Salazar, 1997)—have begun to examine the ways in which such dominance permeates institutions and relationships in this country, while remaining "invisible" to many members of the dominant group (Scheurich & Young, 1997, p. 12; see also Duarte & Rice, 1992; McIntosh, 1990; and McLaren, 1995).

Delpit (1995) asserts that inherent in issues of race, culture and class are issues of power. "Those with power are frequently least aware of—or least willing to acknowledge—its existence," while members of subordinate groups are acutely conscious of the disparities (p. 26). Scheurich (1993; see also Maher & Tetreault, 1997) observes that the longer one group is dominant, the more effectively "the styles of thinking, acting, speaking, and behaving of the dominant group... become the socially correct or privileged ways of thinking, acting, speaking, and behaving" (p. 7):

The ways of the dominant group become universalized as measures of merit, hiring criteria, grading standards, predictors of success, correct grammar, appropriate behavior, and so forth, all of which are said to be distributed as differences in individual effort, ability, or intelligence. Membership in a social group and group-related, inequitable distribution of resources and power thus disappear under the guise of individualism. (p. 7)

The pervasiveness of the mainstream American belief in individualism acts as an extremely powerful filter. As Scheurich (1993) describes it:

Among Whites, the idea that each person is largely the source or origin of herself or himself, that is, individualism, is considered a natural facet of life. Within the frame of this belief, individualism is seen as a naturally occurring, trans-historical, transcultural condition to which all humans naturally aspire. (p. 6)

Stanton-Salazar (1997; see also McIntosh, 1990; Scheurich, 1993; and Tatum, 1997) characterizes this belief "not only as mythical and extremely simplistic, but also ideologically geared to preserve the status quo" (pp. 6-7). Rather, he observes, children "are raised embedded in social networks" that can either "systematically engineer their advantage" or "undermine the support flowing from family and community sources" (p. 31). Emphasizing the importance of "institutional agents" such as teachers, mentors, and advantaged peers, he concludes:

The ideological cloak of individualism serves to obscure how the formation of supportive ties to institutional agents. . . rests on knowledge of, facility with, and deference to the cultural rules, communicative conventions, and network orientations that together are rooted in the social character and ethos of the dominant group. (p. 31)

Racism and "the cloak of individualism."

As McLaren (1995) concludes, "Power relations may not always have a conscious design, but they have unintended consequences which define deep structural aspects of oppression" (p. 53). Moreover, some authors note the convenience of the mainstream belief in individual merit. Delpit (1995) observes, "To act as if power does not exist is to ensure that the power status quo remains the same" (p. 39). Those who reap the tangible benefits of privilege have little apparent reason to question what has always been assumed to be true (Tatum, 1997). And, as constructivist learning theory posits, "In order to take on a new viewpoint, one must decide to let go of an old one. There must be a reason to decide to make a shift in thinking" (Shapiro, 1994, p. 7).

Scheurich and Young (1997), among others, discuss the ways in which the individualist perspective within U.S. culture works to obscure racism and to "keep the thinking about equality or equity incomplete" (McIntosh, 1990, p. 36). The fact that "racism in the U.S. is overwhelmingly seen as an individual phenomenon" (p. 5), they conclude, helps to explain why many mainstream Americans so strongly believe that racism is a limited problem, and react with confusion and hurt when others describe them as part of the problem. Most people do not consider themselves racist: they may, in fact, speak and act against racism. However, Scheurich and Young point out that:

While. . . individualized, conscious, moral or ethical commitment to antiracism is a significant and meaningful individual and historical accomplishment, the fact that it restricts our understanding of racism to an individualized ethical arena is a barrier to a broader, more comprehensive understanding of racism—for society and for researchers. (p. 5)

Scheurich and Young have identified five categories of racism. The first two, "overt racism" and "covert racism," can be defined "as operating at the individual level." "Institutional racism" and "societal racism" are "organizational and social categories" that "create the social context" for individual racism. The fifth category, "civilizational racism," is one which "creates or constitutes the possibility for all of the prior four categories" (p. 4). At institutional and societal levels, racism tends to operate almost invisibly, "like smog in the air" (Tatum, 1997). Differential treatment results not (necessarily) from the conscious intentions of specific individuals, but from the unexamined agreement that "the practices of the dominant group" represent the norms and standards "to which all others must strive" (Aronowitz, 1997, p. 192).

Many scholars and social commentators point out that, in spite of the changes in law and mores in the past four decades, racism persists in all its forms (Lubiano, 1998; West, 1993). Although many mainstream white Americans tend to view violence (such as the 1998 murder of James Byrd in Jasper, Texas) as aberrations, such events are, rather, fostered by the less extreme, more covert forms of racism that permeate U.S. society (Scheurich & Young, 1997).

Inequities and the rehabilitation system.

Much of the discussion about institutionalized patterns of dominance and subordination is couched in broad social terms. Given the statistics regarding the incidence of disability and imbalances in assistance to consumers, there is no reason to believe that rehabilitation is exempt from such systematized inequities. Moreover, any efforts to improve outreach to minority populations must consider the cultural and other contexts in which those efforts are embedded.

A few authors have focused specifically on the systems and institutions intended to assist people with disabilities. Duarte and Rice (1992) for example, conclude that "dominant cultural values related to individualism, self-reliance, and work are evident in rehabilitation legislation, policies, and procedures" (p. 12). Similarly, Harry (1992) notes that "the Education for All Handicapped Children Act couches its mandate in concepts that are uniquely Western, both in terms of a medical model of disability and of a framework of services derived from a technological culture" (pp. 23-24).

Schaller, Parker, and García (1998), in discussing rehabilitation counseling services, observe that the meaning of disability may be constructed differently within different cultures. Yet, "despite a growing recognition of a more comprehensive, environmental conceptualization of disability, rehabilitation counseling continues to use definitions of disability based on pathological and statistical models" (p. 41). They further note that:

Statistical identification of disability lends an air of objectivity in conclusions based on parameters of normalcy defined by a given group. Both the pathological and statistical models of disability, by definition, limit perceptions and interpretations of disability. (p. 41)

Alston and Bell (1996; see also Mohr, 1998) caution that "one attitude that African Americans with disabilities may bring to the rehabilitation process is cultural mistrust" (p. 17). They note that such mistrust is frequently based on negative experiences that African Americans consumers have endured in seeking assistance from the rehabilitation or other service systems. Harry (1992) cites several researchers who have observed "that among low-income Black families, the experience of frequent intrusions by social service workers also contributes to mistrust and unwillingness to cooperate with service providers" (p. 51). She further notes that, "with regard to more ambiguous or mild [disabilities], it has been observed that many African Americans have enduring and well-founded concerns about being misdiagnosed and treated inappropriately by mental health services" (p. 53).

continued

Cultural and other considerations that can influence effectiveness within the rehabilitation system

The complexities of identifying cultural characteristics. Discussions of what are commonly labeled as "cultural differences" between specific groups are inevitably problematic. Most authors focus on what Mason (1994) terms "ethnic cultural groups." "Minority" populations tend to be grouped into the broad categories that, in the U.S., generally are used as racial designations—typically, African American, Hispanic, American Indian, and Asian Pacific American—despite the fact that the categories jumble geographic, racial, ethnic, and cultural characteristics. These groups are contrasted with "mainstream U.S. culture," which is (often implicitly) considered to be white, affluent, and native-born. Race, culture, language, economic and social status, and religious beliefs often are intermingled without explicit consideration of their distinctions or relative importance.

Authors who describe cultural differences generally note that, within each broad category, groups and individuals do vary in terms of nationality, language, religion, and other characteristics. Leung (1996), for example, identifies 47 different cultural groups within the broad category of Asian Pacific Americans. Many also point out that culture is only "one of several significant variables" that influence human interactions (Duarte & Rice, 1992, p. 42). Some reports address other considerations as well, as the following sections describe.

Acculturation. Most authors emphasize that "traditional patterns in all groups may be affected significantly by acculturation" (Harry, 1992, p. 55). Leung (1988, cited in Harry) identifies six factors that appear to most strongly influence acculturation, including "time in the host culture; proximity to the traditional culture, which...deters the acculturation process; age; birthplace; gender, with females being more open to acculturation than males; and intermarriage" (Harry, 1992, p. 14). To this list Harry adds "the variables of social class and educational level" (p. 14).

Several studies describe frameworks for levels of acculturation; though these vary somewhat, they all outline a continuum moving from immersion in one's traditional culture through a bicultural or "dualistic" orientation to immersion in or accommodation to the host culture, with the last stage variously described as "atraditional" (Ramirez & Castañeda, 1974, cited in Harry, 1992, p. 14) or "overacculturation" (Leung, 1988, cited in Harry, p. 14). Soriano (1995) distinguishes between acculturation and assimilation,

characterizing *acculturation* as biculturalism, or the capacity to function in both the traditional and the host or mainstream culture, and *assimilation* as absorption into the mainstream.

Immigrant vs. indigenous groups. Harry observes that "the concept of stages of acculturation is more difficult to apply" to African Americans, "whose native culture was forcibly undermined by slavery, with no allowance for a period of continuing traditional belief and practice" (pp. 14-15). Similar problems apply in considering American Indians and their relationships to mainstream U.S. culture, and some Hispanics as well, since many Mexican Americans have deeper roots in U.S. soil than most white Americans.

Ogbu (1992), among others, has conducted research exploring differences among immigrant and indigenous minority cultures in the U.S. He distinguishes among "autonomous" (for example, some Mormon and Jewish immigrants), "immigrant," and "caste-like" minorities, characterizing the first two groups as "voluntary" and the third group as "involuntary" minorities. Ogbu theorizes that voluntary minorities, believing in the possibility of improving their lives in the United States, are more likely to succeed in school and society than are caste minorities who, experiencing persistent discrimination, "tend to try to preserve linguistic and cultural differences as symbolic of their ethnic identity and their separation from the oppressive mainstream culture" (cited in Minami & Ovando, 1995, p. 438).

A recent study of immigrant children includes findings that reinforce Ogbu's work. The study takes note of students' "rising awareness 'of the ethnic and racial categories in which they were persistently classified by mainstream society'" (cited in Dugger, 1998, p. A11). Researchers found that study participants who began to identify themselves by ethnic categories such as Chicano or Latino had lower grades and higher dropout rates than other participants. This finding "lends support to analysts who have suggested that children of immigrants who come to identify with American minorities may take on 'oppositional' identities" (Dugger, p. A11).

Some researchers, however, argue that Ogbu's categories "are painted with too broad a brush stroke" (Zentella, 1997, p. 272). Valdés (1997), in discussing children of Mexican origin, notes that both voluntary and involuntary minorities "exist within this single population" (p. 406). Zentella makes a similar observation regarding students she studied in a Puerto Rican neighborhood in New York City, noting further that "any model that polarizes accommodation and resistance cannot capture the ways both coexist in the daily lives" of the students she observed (p. 273). Trueba (1989, quoted in Harry, 1992) also criticizes Ogbu's framework for "its inability to account for the success of many so-called caste-like minorities" (p. 20).

Racial identity development. Considerations of assimilation and of immigrant and indigenous minorities also must take race into account. Harry cites work by Spener (1988), who points out

that the racial background of immigrants is important because, after the "outward ethnolinguistic markers" are no longer evident, racial differences are. Consequently children of immigrant racial minorities remain minorities, while the children of White immigrants become part of the majority. (Harry, p. 17)

Some researchers, particularly those focusing on African Americans, emphasize racial rather than cultural identity, with cultural considerations being subsumed within those of race. Alston, Bell, and Feist-Price (1996) describe racial identity in terms of four dimensions:

Racial identity development may be defined as the process through which an individual examines the psychological (sense of belongingness and commitment), cultural (awareness, knowledge, and acceptance of cultural and social traditions), physical (acceptance of physical features of the racial group) and sociopolitical (attitudes toward social and economic issues of the racial group) aspects of being a member of one's racial group along with the value and emotional significance associated with that membership. (p. 11)

A psychological theory of African American racial identity development described by Cross (1995) is frequently used as a framework for discussions of racial identity. This theory describes "the psychology of becoming Black" (p. 94), a multi-staged process through which individuals move "in the transformation of... a non-Afrocentric identity into one that is Afrocentric" (p. 97). This theory has been adapted and applied not only to other minority populations, but also to considerations of racial identity development among whites (Cross, 1995; see also Tatum, 1997).

Distinguishing cultural factors from socioeconomic status. Many scholars discuss "the danger of confusing culture with socioeconomic level," observing that "much of what is thought to be culturally derived is actually a result of economic conditions" (Smart & Smart, 1992, p. 31). As an example, Harry (1992) points out that "the stereotype of the absent Black father is tied to economics and class rather than being characteristic of African Americans as a whole" (p. 49). Some reports on cultural differences that influence the effectiveness of rehabilitation services discuss the need for programs that are easily accessible (meaning, in this instance, located within the client community), that offer flexible service hours, or that offer assistance with child care (see, for example, Duarte & Rice, 1992; Flaskerud, 1986). While these are important considerations in improving access to services, they are a function of socioeconomics rather than of culture. Smart and Smart conclude:

Poverty may lie at the root of many behaviors which could be misdiagnosed as having an internal locus... Upon closer inspection... it becomes apparent that "free" services are costly when the client must leave work, pay for child-care, pay transportation costs, and provide an interpreter, all problems with an economic basis rather than a cultural or psychogenic basis. (p. 32)

Some writers have suggested that the condition of poverty itself has given rise to a distinctive cultural group. As Luft (1995) describes it, poverty "frequently is viewed as a distinctive subculture of American life, and one that carries with it an intergenerational cycle" (p. 13). However, McLemore (1994) reports that "most of the research conducted to determine whether poor people do, as claimed, possess a specific, distinctive culture has not supported this idea." He further notes, "Many critics see the culture of poverty thesis... as an elaborate way to shift the responsibility for social change away from the majority and onto the shoulders of the minority," a process characterized as "blaming the victim" (p. 342).

Facing the dilemma. Given the complexities described above, most authors acknowledge the severe limitations of cultural characterizations but then proceed to make them. The dilemma lies in the question posed by Tatum (1997): "How can I make the experiences of my Latino, Asian, and Native students visible without tokenizing them?" (p. 132). She concludes, as do most scholars pursuing this topic, that "a sincere, though imperfect, attempt to interrupt the oppression of others is usually better than no attempt at all" (pp. 132-133).

Descriptions of mainstream culture in the United States. As noted earlier, the norms and beliefs of mainstream U.S. culture shape the organizational goals, policies, norms, procedures, and interactive styles of most organizations and institutions in this country. Very few reports, however, attempt to profile these characteristics except as they contrast with characteristics identified for other cultures. As is true with other broad cultural categories, "mainstream U.S. culture" is an encompassing term that belies the diversity of those it includes. Descriptions of what it means to be "in the mainstream" generally refer to white, middle-class Americans. Other significant characteristics are often mentioned as well, as the following sections discuss.

"Whiteness." Though a person does not necessarily need to be "white" to participate in mainstream U.S. culture, characteristics of those in the mainstream are inextricably tied to that dubious but powerful racial designation. Maher and Tetreault (1997), citing Thompson et al., attempt to make sense of this apparent paradox by

continued

Descriptions of mainstream culture in the United States. *continued*

distinguishing among "Whiteness as description," referring to the assignment of racial categories to physical features, "Whiteness as experience," referring to the daily benefits of being White in our society, and finally, "Whiteness as ideology," referring to . . . beliefs, policies, and practices. (p. 324)

Individualism. The literature describes *individualism* as one of the most dominant values operating in mainstream U.S. culture. Rehabilitation counseling and the work of independent living centers, for example, focus on the individual with a disability; services, procedures, and rules are geared to that person. However, Leung (1993) notes that "one of the common elements in the value/belief systems of all four major minority groups is the emphasis on the group, rather than the individual" (p. 96). With a "collectivist" rather than an individualist orientation (Gudykunst & Ting-Toomey, 1988, p. 40), decisions may be based on the needs of the family group rather than on those of one particular member. Hong (1995), in discussing Asian Pacific cultures, describes this orientation as *familism*:

As opposed to individualism in Western cultures, Asian cultures are focused on the family. . . . The idea of familism prescribes that the family is more important than the individual. The welfare of the family takes precedence over the welfare of the individual. (p. 60)

The focus on the individual functions not only as a goal but also as an explanation for differences in status and achievement. As discussed earlier, individualism helps to mask social inequities by attributing "success" and "failure" to the behavior and characteristics of each person rather than to patterns of access and opportunity (Harry, 1992; Scheurich & Young, 1997). The pervasiveness of this belief is illustrated in the results of a study by Conner (1988), who examined the approaches used in health promotion and disease prevention programs in a number of western and eastern countries. Conner found that:

The U.S. programs emphasize changes that the individual is supposed to make in his or her behavior; success or failure is very much dependent on individual effort. Likewise, attributions for success or failure are focused on the individual (good personal will-power, in one case; lack of conviction or self-control in the other), as are the outcomes of success or failure (an improved or diminished self-confidence, for instance). (p. 182)

This orientation contrasts strongly with approaches used in other countries. For example, Conner observes, "In Western European countries, the medical model is mixed with and sometimes superseded by a public health model with more focus on groups and communities and much less on individuals" (Conner, 1988, p. 182). In eastern countries, there is "a strongly individualist focus, in that different balances are appropriate for different individuals." However, this perspective is

mixed with a strong community focus, in that complex belief systems surround activities of daily life. . . . The respect for individuals which is a part of these systems is very different from the respect for individuals that characterizes the western approach, particularly the strongly-individualistic U.S. approach. Individuals in the Eastern view have limited power to change their current situation; individuals in the Western view are seen as nearly all-powerful in changing their current situation. (p. 183)

High vs. low context. Duarte and Rice (1992) note that the literature of intercultural communication emphasizes "cultural differences related to context," which they characterize as "the information that surrounds events" (p. 17). Harry (1992), among others, cites Hall (1977), who "used the concept of 'high- and low-context' cultures to describe the potential of the law in various societies to address human issues in a more or less personalistic manner." Mainstream U.S. culture "is, in comparison to that of many other countries, markedly 'low-context' in its reliance on positivistic criteria for truth and in its tendency to exclude and treat as irrelevant the complexities of human perception and personal interaction" (pp. 111-112).

In this country laws, policies, procedures, application criteria, and other requirements are designed to be "low context," independent of circumstance and equally applicable to the full spectrum of the populations addressed. The intent of such an approach is often fairness, for example, stating job requirements as concretely as possible so that all applicants are judged according to the same criteria and none receives preferential treatment. But since mainstream cultural standards are embedded in these requirements, as well as in the expectations and perceptions of the gatekeepers who apply them, the rules become skewed toward those in the mainstream (Scheurich & Young, 1997; Tatum, 1997).

The concept of low versus high context also applies to communicative styles, particularly in organizational or service settings. Harry explains that,

In high-context communication there is a tremendous reliance on personal delivery, which may include affective as well as factual information, thus making meaning dependent on personal interaction. By contrast, low-context communication relies, according to Hall, on the actual language code isolated from the interpersonal aspects of communication. The goal of this form of communication is a

high level of objectivity—on the assumption that such objectivity reflects greater precision in meaning. The latter will only be true, however, if both parties in the communicative act hold shared meanings of the language being used. (p. 172)

Harry further notes that members of the mainstream culture who work in service settings tend to combine a casual, informal style of greeting and speech with a low-context, impersonal approach to the content of the conversation. For members of most non-mainstream cultures, "an underlying commonality is a frequent discomfort with the informal and egalitarian approach typical of most White Americans." She recommends that those in professional settings, at least initially, should "approach culturally different families in a polite and more formal manner. . . . while striving to create communication that is personal rather than impersonal" (p. 57).

Valuing reason, science, and technology. Haymes (1995) and others note the emphasis in mainstream U.S. culture on rationality, the positivistic pursuit of scientific "truths," and technological advancements. These beliefs exert a particularly strong influence on approaches to rehabilitation and education (Schaller, Parker, & García, 1998; Scheurich, 1993; Duarte & Rice, 1992).

Attitudes regarding disability. As suggested above, attitudes about the causes and appropriate responses to disability within mainstream U.S. culture are strongly influenced by beliefs in individualism, rationality, and science. The medical model, which is structured to identify "disease" and treat it largely in isolation from other aspects of a patient's life, permeates mainstream perspectives regarding disability (Conner, 1988; Duarte & Rice, 1992; Harry, 1992).

Descriptions of "ethnic cultures" in the United States.

African Americans. Considerations of culture within the broad category of *African American* are extremely complex. Most African Americans have a long ancestry in the U.S. (Takaki, 1995). For many, however, their position in U.S. society is marginal to that of the mainstream. At the same time, links to their cultures of origin have been attenuated (McLemore, 1994). In addition, African Americans are diverse in terms of education, economic status, religious belief, degree of urbanization, and other characteristics (Tatum, 1997). Lubiano (1992) observes that:

In our attention to the history of racism in the United States, African Americans have learned to keep in our memory the unrelenting attacks on our existence as a group. . . . But blackness is simply too large and unelaborated a category to carry the weight of analysis. (p. 346)

While it is inaccurate to speak of "Black culture" in monolithic terms, African Americans tend to remain in touch with what Lubiano (1992) describes as "a conscious awareness of being part of a group. . . with a particular place in history and a political relationship to other groups within the. . . United States" (p. 330). In addition, some African Americans share affiliations and world views that are grounded in elements of traditional African cultures, Protestantism, and adaptations to the experiences of indenturehood, slavery, and subordination in U.S. society (Takaki, 1995; Harry, 1992). Cross (1995), in discussing racial identity development, observes that not all African Americans develop a Black identity. For those who do, however,

Having a Black identity means that the reference group functions of one's identity are grounded in one's Blackness. . . . One's values, cultural preferences, artistic tastes, leisure activities, cooking styles and food choices, secular and religious musical tastes, church affiliation, organizational memberships, and social network or intimate friends are all influenced by one's perceived connection to Black people. In brief, some or a great deal of the meaning and hope one has for living a purposeful life is linked to one's perception of oneself as an African American. . . . Whether it is mingled with other identities or singular, being Black plays an important reference group function in the daily life of the person. (p. 119)

Jackson and Sears (1992, cited in Leung, 1993) describe an "Africentric" world view as characterized by a "group orientation, collective responsibility, cooperation, and interdependence" (Leung, p. 96). Similarly, Harry notes that Protestantism within Black culture "emphasizes group solidarity and collectivity" (p. 48). McLemore (1994) cites a number of sources that emphasize the importance of extended families, noting that "accumulating evidence supports that the extended family, rather than the nuclear family, is the proper unit of analysis" for studies of African American families (p. 328). He reports that "regardless of income level, African Americans are significantly more likely than white Americans to have extended family members living in the household" (p. 330).

In terms of attitudes regarding disability, studies suggest that many African Americans attribute "significantly more importance to spirituality in causing and treating" developmental and other disabilities. Instead of, or in addition to, seeking help through medical or rehabilitation systems, many African Americans rely heavily on community supports, particularly the church (Leong, Wagner, & Tata, 1995, p. 423). Harry, Allen, and McLaughlin (1995, cited in Schaller, Parker, & García, 1998) also point out that African American parents "may hold broader perceptions of normalcy and have a wider range of expectations for developmental milestones of children's behavior" than do many educational professionals (p. 41).

Descriptions of "ethnic cultures" in the United States.

continued

Traditional Hispanic cultures. Soriano (1995), discussing culturally appropriate rehabilitation counseling for Latino populations, observes that "Latinos are highly diverse... in terms of culture, ethnicity, and geographic origin, as well as in terms of education and economic levels" (p. 67). However, within this diversity, many scholars find a number of commonalities in customs, beliefs, and world views. Harry (1992), for example, lists characteristics common to traditional Hispanic world views. She characterizes traditional Hispanic culture as "based on Catholic ideology, with an inextricable interweaving of the ideologies of native Central and South American views of the universe" (p. 26). In Caribbean territories, however, "it is mainly African religious beliefs that have been added to a Catholic base" (p. 26). Other characteristics cited by Harry and others include:

- "the centrality of the concept of 'familia,'" with "a clearly defined hierarchy of authority" within the family structure (p. 29, quoting Ramirez & Castañeda, 1974)
- "respeto," also described as "dignidad," "personalismo," or "confianza" (p. 29), all terms referring to "a personalized yet ritualistic respect" that is based on selfhood rather than on achievement, and which "makes it difficult for an individual from traditional Hispanic culture to be comfortable with North American-style 'professionalism,' which assumes due respect on the basis of one's possession of specific skills" (p. 30), and
- devaluation of darker-skinned peoples and placement of a high valuation on social status (p. 30).

As is described for other non-mainstream groups, perspectives on disability among members of traditional Hispanic cultures are influenced by beliefs in the intersection of the physical and the spiritual (Smart & Smart, 1992). Families, which act as a powerful support system (Leong, Wagner, & Tata, 1995) consider some conditions as merely a reflection of individual differences rather than disability, and adapt family and work roles to accommodate those differences. However, severe disability, especially developmental disability, is a stigma for the traditional Hispanic family (Harry, 1992).

Many traditional Hispanic families, though they may seek assistance from mainstream health systems, also may seek help from folk healers and members of the clergy. Leong, Wagner, and Tata (1995), in discussing mental health services, cite findings that "utilization of folk healers is not common, particularly among urbanized, acculturated Hispanics" (p. 427). However, they also cite a study by Martinez and Martin (1966), which found "that approximately 97% of the 75 Mexican American housewives they surveyed were familiar with folk remedies and more than 50% had been treated by a folk healer" (p. 427). Trevino (1991) concludes that:

To many Mexican Americans both traditional health services and folk healing are important, each addressing different needs in different ways. . . . Rehabilitation counselors who serve many Mexican Americans should seriously consider building relations with folk healers. After all, they may be viewed as simply another allied health professional offering rehabilitation services from a different cultural perspective. (p. 24)

Traditional Asian Pacific cultures. Leung (1993) notes that "no ethnic group in the U.S. is as difficult to describe as Asian Americans" (p. 95). Harry (1992) also describes "vast racial differences" among groups in this category, as well as differences in religion, language, and culture, but identifies "certain commonalities" (p. 35). She observes that "the essence of Eastern cultures is collectivism and harmony" (p. 35). Quoting Chan (1986), she summarizes the common features in Eastern cultures as

harmony, social order, rules of propriety, filial piety, benevolence, loyalty, cooperation, reciprocity, and obligation, all of which exist within a system of "prescribed roles and relationships which emphasize subordination and interdependence"... A belief in "the supremacy of the universal order over oneself is further manifested in reverence for the past." (p. 35)

In discussing Americans of Chinese descent, Chan, Lam, Wong, Leung, and Fung (1988) contrast the individualistic orientation of U.S. mainstream culture with "the Chinese preoccupation with social order (collectivist orientation). This concern of the Chinese people for harmony-within-hierarchy is strongly influenced by Confucian philosophy and often continues to be an influence on Americans of Chinese descent" (p. 21). They observe that the emphasis in traditional Chinese society on "functioning within well-defined and structured social relationships" may lead some Chinese Americans to "expect the same well-defined structure and role in a [rehabilitation] counseling relationship. The client-centered approach used by many rehabilitation counselors in the United States may be viewed as too ambiguous and 'wishy-washy' by Chinese-American clients" (p. 22).

In a similar vein, McFarlane, Farley, Guerrero, and Galea'i (1996), discussing Pacific cultures in areas served by the Rehabilitation Research and Training Center of the Pacific, describe how these differences influence concepts related to independent living: "The concept of independent living when described by such terms as empowerment, advocacy, personal choice, and living independently, goes against Pacific Island cultural practices of respect, being humble, . . . family choice and involvement, and living and being with the family" (p. 24).

As do other authors (see for example, Harry, 1992; Hong, 1995), McFarlane et al. stress the importance in traditional Asian Pacific cultures of family life and the preservation of family honor. They explain that, in traditional Samoan culture, for example, "a person has an identity only so far as that person can demonstrate his/her connections to the *aiga*

(extended family). Personal needs, goals, and eccentricities must be downplayed for the good of the family group" (p. 25). They further observe that, "in Samoa and throughout most of the Pacific, there remain strong inhibitions against airing family problems to outsiders" (p. 25).

Yamashiro and Matsuoka (1997), discussing the underutilization of mental health services among Asian and Pacific Americans, note the concept of "face," which is reinforced by Confucian philosophy. They conclude that traditionally oriented Asian and Pacific Americans "may perceive that losing face because of mental illness in the family would subject the individual or family to a religious or spiritual crisis" (p. 182).

In terms of attitudes about disabilities, Leung (1996) cites Paris (1993), who "found that Asians generally had the least positive attitudes [toward people with disabilities], even when healthcare professionals are the subjects of research" (p. 5). As Hong (1995) explains,

There are many [Asian Americans] who believe in supernatural or metaphysical forces which could play a role in health and disease, and in fortune and misfortune. Such beliefs have strong implications in the perception of the causes of disability, in the treatment of disability, and in the feelings of guilt, responsibility or shame associated with having a person with a disability in the family. (p. 61)

Traditional Asian Pacific Americans often seek help through sources other than, or in addition to, the western medical or rehabilitation system. Hong observes that "a family will often want to pursue traditional Asian cures, such as herbal medicine, or take certain actions to restore the balance of nature" (p. 61). Liu (1995) notes that "Asian Americans rely more heavily on informal social networks" than do most other minority groups (p. 125).

American Indian cultures. Quoting Trimble (1990), Leung (1993) explains that "the term American Indian can be viewed as 'an imposed social and political ethnic category with little relevant meaning,' and represents 'a range of cultural orientations'" (p. 95). Leung notes the existence of more than 500 tribal groups that have been recognized by the U.S. government. Harry (1992) points out the dangers of ignoring the diversity inherent within these groups as well as other factors. She concludes:

To the extent that there can be said to exist a Native American culture in the United States, it must be seen as the product of three centuries of contact with U.S. mainstream culture and the imposition of alien forms of government, philosophy, and social organization on varying traditional cultures of Native American peoples. . . . Contemporary Native American groups hold certain features in common, which may be, to varying extents, a combination of traditional features, adaptive strategies, and varying levels of acculturation to the dominant culture. These features

include an enduring sense of pride in cultural heritage, a belief in the interrelatedness of body and spirit, culturally distinctive communication styles, and a reliance on extended community and kinship networks. (p. 40)

Harry notes among Native American groups "a style of communication that is consistently described in the literature as less verbal and direct than that of mainstream U.S. culture" (p. 44). This indirect style, along with standards of courtesy and appropriate interaction, lead Locust and Lang (1996) to conclude that, "if a [rehabilitation] counselor wished to observe courteous behaviors with an [American] Indian client, the time spent with that one client would double or triple what might be necessary for other clients" (p. 5).

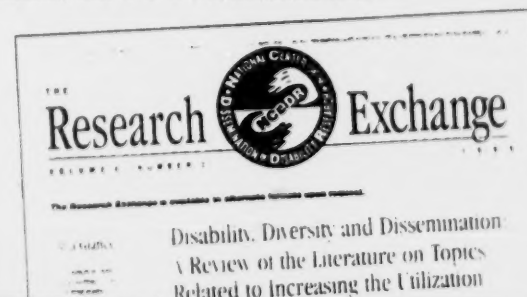
Regarding concepts of disability among American Indians, Locust (1988, cited in Harry, 1992) observes "that most traditional Indian languages do not have words for retarded, disabled, or handicapped and, rather than using such categories, may assign names of individuals that are descriptive of the disability, such as One-Arm, or One-Who-Walks-with-a-Limp" (p. 46). The belief in the interrelatedness of body and spirit described by Harry and others contrasts with the beliefs inherent in the mainstream medical model. As is true in other traditional cultures, American Indians with strong roots in traditional tribal culture may seek help from "folk healers" as well as the mainstream medical and rehabilitation systems.

A Look Ahead to Part 2:

Applying the Concepts to Research and D & U

This ends Part 1, which offers a discussion of the theoretical framework describing the relationship of constructs such as race, ethnicity, culture, disability, and power. Influences within the rehabilitation system were presented, as well as descriptions of "mainstream" and "ethnic" cultures in the United States.

Volume 4, Number 2 will focus on the characteristics of effective systems and how to build relationships within "culturally competent" organizations. The concepts about culture and diversity that were presented in Part 1 will be related to issues in conducting research and issues in dissemination and utilization. The conclusion will offer organizational, research, and D & U recommendations.



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Wednesday, January 13, 1999

President Clinton and Vice President Gore: Economic Opportunities for All Americans

Increased access to health care; more assistance at home and in the workplace; remarkable new technologies: that is how we will make sure that all Americans, no matter what their abilities, can take their place in the workplace.

—President Bill Clinton

On January 13, 1999, President Clinton unveiled a historic new initiative that will remove significant barriers to work for people with disabilities. This three-part budget initiative, which invests \$2 billion over five years, will help provide better health care options for people with disabilities who work, a \$1,000 tax credit for work-related expenses, and invest in technology that can enhance their ability to participate in the workplace.

Removing The Barriers That Stop People With Disabilities From Going To Work. Since the President and Vice President took office, the American economy has added 17.7 million new jobs, and unemployment is at a 29-year low; however, the unemployment rate among working-age adults with disabilities is nearly 75 percent. People with disabilities often become ineligible for Medicaid or Medicare if they work, putting them in the difficult position of choosing between health care coverage and work. In addition, advances in technology and communications are often not accessible to people with disabilities.

A Historic Plan To Improve Economic Opportunity For Americans With Disabilities. The President's budget proposal will include a three-part initiative to bring greater opportunity to Americans with disabilities:

- **Funding the Work Incentives Improvement Act.** Health care, particularly prescription drugs and personal assistance, is essential for people with disabilities who work. The President's budget fully funds the Work Incentives Improvement Act, that would improve access to health care by:
 - Expanding states' ability to provide a Medicaid buy-in to people with disabilities who return to work;
 - Extend Medicare coverage, for the first time, for people with disabilities who return to work;
 - Create a new Medicaid buy-in demonstration to help people with a specific physical or mental impairment that is not severe enough to qualify for health assistance, but is likely to lead to a severe disability in the absence of medical treatment;
 - Modernize the employment services system by creating a "ticket" that will enable SSI or SSDI beneficiaries to use a range of public or private providers for vocational rehabilitation. If the person goes back to work and achieves substantial earnings, providers would be paid a portion of the benefits saved; and
 - Create a Work Incentive Grant program to provide benefits planning and assistance, facilitate access to information about work incentives, and better integrate services to people with disabilities working or returning to work.
- **Providing a \$1,000 Tax Credit For Work-Related Expenses For People With Disabilities.** Under the President's proposal, workers with significant disabilities would receive an annual \$1,000 tax credit to help cover the costs associated with employment, including, special transportation and technology;
- **Improving Access to Assistive Technology.** This new initiative will accelerate the development and adoption of information and communications technologies that can improve the quality of life for people with disabilities and enhance their ability to participate in the workplace.

Source: The White House at Work Archives: <<http://www.whitehouse.gov/WH/Work/011399.html>>



Photo courtesy of the White House

Judith Harkins, Ph.D., (Gallaudet University) Co-Principal Investigator of the Rehabilitation Engineering and Research Center on Universal Telecommunications Access, shows President Clinton the accessibility features on a telephone handset. Looking on are Vice President Al Gore; Katherine Seelman, Ph.D., Director, National Institute on Disability and Rehabilitation Research (NIDRR); and Gregg Vanderheiden, Ph.D., (Trace R&D Center) Co-Principal Investigator of the RERC on Universal Telecommunications Access

President's Initiative to improve economic opportunities for people with disabilities

On January 13, 1999, Dr. Katherine D. Seelman, Director of the National Institute on Disability and Rehabilitation Research (NIDRR), participated in the White House announcement of a major new multi-faceted initiative to improve economic opportunities for people with disabilities. As a part of the event selected NIDRR grantees set up displays in the Grand Foyer of the White House highlighting examples of assistive/adaptive technologies and universal design for people with disabilities. The announcement included a technology initiative for people with disabilities that was presented by the President to the Congress in the FY 2000 Budget.

NIDRR has a long history of work to support assistive technology and universal design for people with disabilities through its Rehabilitation Engineering Research Center (RERC)

Program. In addition, NIDRR manages the State Technology Assistance Program funded through the Assistive Technology Act of 1998 and NIDRR has funded special projects to heighten awareness of assistive/adaptive technologies through dissemination projects such as ABLEDATA. Despite these efforts, new technologies often remain difficult to access by some people with disabilities. A part of the President's Initiative is designed to increase access to needed technologies. The President's Initiative accelerates the development and adoption of new information and communications technologies that can improve the quality of life for people with disabilities and enhance their ability to participate in the workplace.

Source: <http://www.ncddr.org/news/1_13news.html>



NIDRR Grantees Receive Recognition

The NCDDR congratulates each of the following NIDRR grantees. All grantees are encouraged to contact the NCDDR with information to share in future issues of *The Research Exchange*.

~

Dr. Catherine A. Marshall, CRC, and **Ms. Mikel Johnson, CRC**, received the *Outstanding Researcher of the Year Award* from the National Council on Rehabilitation. These researchers from the **American Indian RRTC (AIRRTC)** at Northern Arizona University, were recognized in March, 1997, for their research on counseling Native Americans. **Dr. Marshall** is the Director of Research for AIRRTC and **Ms. Johnson**, a faculty member at Emporia State University, served as a contract researcher. For further information, contact the AIRRTC Project Director, **Dr. Priscilla Sanderson**, at 520-523-4791 or by e-mail: priscilla.sanderson@nau.edu

~

Dr. Judith E. Harkins, Principal Investigator of the **RERC on Universal Telecommunications Access**, was honored by Telecommunications for the Deaf, Inc. (TDI) as one of 30 individuals who have produced the greatest impact on telecommunications accessibility for America's deaf and hard of hearing citizens from TDI's inception in 1968 until the present. The award was presented in December, 1998 at a gala celebrating TDI's 30th anniversary. **Dr. Harkins** was also recognized in the 30th anniversary commemorative issue of TDI's *GA-SK Newsletter*.

In June, 1997, she was honored by Self-Help for Hard of Hearing People (SHHH) at its annual convention, with the *Special Friend of People Who are Hard of Hearing Award*. This national award cited **Dr. Harkins**, in her roles as researcher and educator, as a "constant force in expanding communication access and therefore the quality of life for people who are hard of hearing." For more information, contact **Dr. Harkins** at (202) 651-5257 or by email: judy.harkins@gallaudet.edu

~

Dr. John H. Maxson, Training Director, **RRTC on Blindness and Low Vision**, received the *Outstanding Service Award* from the Mississippi Association for Education and Rehabilitation of the Blind and Visually Impaired (MAER). This award for "overall excellence in the field of blindness and low vision" was presented at the MAER annual conference on August 21, 1998. **Dr. J. Elton Moore** is the Principal Investigator for the RRTC, located at Mississippi State University. For further information contact **Dr. Maxson** or **Kelley Schaefer**, Dissemination Specialist, at (601) 325-2001 or by e-mail: jhm51@ra.msstate.edu or schaefer@ra.msstate.edu

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A LOOK BACK TO Part 1: Theoretical Framework

At a Glance *inside this issue*

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The review of the literature presented here and in the previous issue (Volume 4, Number 1 of *The Research Exchange*) was prepared to help researchers better understand the interaction of disability, diversity and dissemination. **Part 1: Theoretical Framework** presented a discussion of the relationship of constructs such as race, ethnicity, culture, disability, and power. Influences within the rehabilitation system were presented, as well as descriptions of "mainstream" and "ethnic" cultures in the United States.

Part 2 focuses on the characteristics of effective systems and how to build relationships within "culturally competent" organizations. The concepts about culture and diversity that were discussed in Part 1 are related to issues in conducting research as well as issues in dissemination and utilization (D&U). Organizational, research, and D&U recommendations are also presented.

Disability, Diversity and Dissemination: A Review of the Literature on Topics Related to Increasing the Utilization of Rehabilitation Research Outcomes among Diverse Consumer Groups

PART 2 - APPLYING THE CONCEPTS TO RESEARCH AND D&U

Characteristics of effective systems and relationships

How is all of the information presented in **Part 1: Theoretical Framework** linked to the process of increasing the utilization of rehabilitation research outcomes? Addressing diversity in the knowledge utilization process is not merely a matter of translating materials into Spanish or broadening dissemination channels to include, for example, churches in predominantly African American communities. For most research and development organizations, and for the service agencies that often serve as dissemination channels for them, addressing diversity requires fundamental changes in perspective in order to become knowledgeable about, responsive to, and credible to a diverse set of potential users. There are

A WORD FROM THE DIRECTOR

Effective Outreach to Diverse Groups

Americans represent a rich diversity of characteristics and conditions. It seems that more is known about Americans today than ever before. For example, information is available today that suggests how many of us live in rural versus urban settings, how many of us are financially richer and how many are poorer, and so on.

Debates continue concerning how many of us are disabled, however. Depending on the criteria used, estimates vary from a low of about 36.1 million (LaPlante, 1992) to about 54 million (NCD, 1997). No matter how you identify and count Americans with disabilities, however, this segment of the population is also rich in its diversity of characteristics. While this diversity is obvious, it can present some interesting challenges to those conducting research addressing disability issues.

Common sense tells us that "one size does not fit all" when it comes to research outcomes. Many times, dissemination practices tend to suggest that the outcomes of disability researchers can be equally utilized, and are equally beneficial regardless of one's ethnic, cultural, social, economic, demographic, linguistic, or other characteristics. Just as research designs must be carefully constructed and implemented, reports of research outcomes must also be carefully expressed in order to clarify how the research results might most appropriately be used.

Dissemination strategies should also be carefully considered and targeted to facilitate utilization by designated audiences. These strategies should not promote over-generalization of research findings. The diversity of Americans with disabilities should influence not only how research activities are conducted but also how we plan and implement effective dissemination and utilization strategies in an increasingly diverse world. Our challenge is magnified by understanding that in the real world Americans with disabilities do not make up a homogenous population.

This issue of the NCDDR's *Research Exchange* continues a review of the literature relevant to dissemination, disability, and diversity. Clearly, no simple formula exists to dictate dissemination strategies that will be successful with all audiences. NIDRR grantees should be aware of many factors and options that affect our effectiveness in achieving utilization across diverse groups of Americans.

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Characteristics of effective systems and relationships

continued from page 1

implications for organizational policy, structures, procedures, and staffing; for what research is conducted, for what purposes, and according to what methodologies; and for strategies for "packaging" and disseminating research outcomes. These implications are discussed in the following sections.

Building "culturally competent" organizations.

Most of the literature addressing organizational issues related to diversity focuses on service agencies rather than on research agencies and organizations. However, many of the principles and characteristics described for service agencies also appear relevant to a variety of institutional contexts. This literature includes recommendations for organizational approaches that are variously described as "culture-compatible" (Flaskerud, 1986) or "multicultural" (Duarte & Rice, 1992; Ehiobuche, 1995). A number of authors use the term "cultural competence," a concept derived from the work of Cross et al. (cited in Benjamin, 1992; see also Schaller, Parker, & García, 1998; Soriano, 1995; and Mason, 1994).

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Soriano defines cultural competence as "a set of congruent behaviors, attitudes, beliefs, and values that enable [people] to work effectively in a cross-cultural situation" (p. 67). Benjamin notes that developing "culturally competent systems of care" requires "congruence" among policymakers, administrators, practitioners, and consumers; he lists five "essential elements" that characterize culturally competent organizations. With slight variations, this list is echoed by Soriano:

- valuing diversity "for its own sake" (Soriano, p. 68);
- having "the capacity for cultural self assessment" within the organization (Benjamin, p. 39);
- institutionalizing knowledge about various cultural groups;
- fostering consciousness among all staff as to "the dynamics inherent when cultures interact" (Benjamin, p. 39); and
- having the "willingness and ability to adapt to a diverse and continuously changing cultural mosaic in society" (Soriano, p. 68).

Benjamin and his colleagues conducted a nationwide study to assess organizational characteristics that help to operationalize these elements of cultural competence. They found:

Some of the dominant characteristics of programs that exemplified culturally competent principles/values were: . . . clearly defined philosophy and policies (the more clearly articulated the program philosophy and policies based on cultural dynamics and inclusion, the more culturally competent the programs tended to be); . . . strong emphasis on the importance of family as defined by the culture; staffing patterns that reflect the ethnic makeup of the population served; [and] an emphasis on training, education, and curriculum development to address cultural issues. (p. 39)

Empowerment vs. assistance. The most critical element of cultural competence, according to some authors, is "empowerment," an orientation toward partnership with clients or consumers rather than assistance that is "bestowed" upon a passive recipient. As Kalyanpur and Rao (1991) explain,

Empowerment signifies changing the role of a service provider from that of an expert to that of an ally or friend who enables families to articulate what they need . . . It involves caring, which builds supportive relationships; respect, which builds reciprocity; and the acceptance of differences, which builds trust. (p. 31)

Wolff (1995), citing the work of Chavis and Florin, summarizes major differences between traditional approaches, in which research, services, or information are provided by outside "experts" to an essentially passive recipient audience or clientele, and an empowerment approach, in which providers and clients work as partners. Wolff

FIGURE 1

Differences between traditional and empowerment approaches

Traditional/ Community based	Empowerment/ Community development
Problems defined "by agencies, government and outside institutions"	Problems defined by the community
Primary vehicles for change are "information, education, and . . . capacity"	Primary vehicles for change are "building community control and increasing community services"
Professionals "are the key and central decisionmakers"	Professionals "are a resource to the community's problem solving"
Primary decisionmakers are "agency and government representatives and other appointed leaders"	Primary decisionmakers are "the indigenous, informal and elected leaders from the community" (p. 2-17)

uses the term "community based" to describe traditional approaches and "community development" to describe empowerment strategies:

Some authors also discuss the need for service agencies to shift their orientation from that of solely addressing the needs of individuals to including a focus on underlying social, institutionalized inequities. For example, Ehiobuche (1995), describes a "multicultural rehabilitation modality" as requiring "an equally balanced focus on the environment and on the individual because disability may stem as much from environmental barriers (cultural racism, poverty, and disadvantaged status) as from the individual's functional limitation" (p. 53). Similarly, Atkins (1988), in discussing mental health services for African American clients, quotes Raphael (1972), who notes that "the counselor is caught between efforts to ameliorate the immediate problems of a particular client and an awareness that only deeper social reform can eliminate the general conditions creating the problems" (Atkins, p. 45). And Brodwin, Orange, and Brodwin (1995), pointing out that people with disabilities are stigmatized in U.S. society, argue that "it is the responsibility of the rehabilitation counselor to tactfully and artfully stimulate various aspects of our society to address the anti-discrimination regulations of the ADA" as well as other provisions designed to prevent discrimination against particular groups (p. 87).

Addressing organizational policy as well as practice.

Mason (1994) notes that "the policy element is an often overlooked—yet very important—area" of cultural competence within organizations. "Culturally competent staff attitudes and program practices need to be upheld by policy lest they ebb and flow on the trends of the times" (p. 6). Similarly, O'Brien and Rhoades (1996), in discussing outreach and rehabilitation

continued

Building "culturally competent" organizations. *continued*

services for non-English speakers, recommend that agencies that are "serious about improving services to non-English-speaking clients must begin with an organized outreach plan." They stress that "the plan should not be placed solely on the shoulders of one person—for example, the bilingual staff member—but should be a cohesive teamwork effort to which all staff members are committed" (p. 8). Duarte and Rice also address the importance of aligning policy and practice:

The VR agency should be an organization which values diversity and emphasizes that value in its mission, policy, principles, procedures, and practices. It is critical that organizational leaders demonstrate a commitment to this value in theory and practices which guide agency activity. The integration of this value into the organization is not a "quick fix" process achieved by brief training programs. (p. 43)

Diversifying staff. Perhaps more than any other single characteristic, the literature stresses the need for the staff of culturally competent organizations to reflect the racial, ethnic, and cultural diversity of intended consumers. For example, Atkinson and Lowe (1995), who reviewed research studies on mental health counseling, found "strong evidence" that pairing clients with "ethnically similar" counseling professionals is "associated with more positive counseling process and outcome" than if the client and professional are "ethnically dissimilar" (p. 405). Flakerud (1986) identified "nine major components of a culture-compatible approach recommended by researchers to the mental health care of Asian, Hispanic, and Black American clients" and then conducted a study to assess the influence of each component on the dropout rate among minority clients within mental health service organizations. The study found that, "of the individual components, language match of therapist and client, ethnic/racial match of therapist and client, and agency location in the ethnic/racial community were the best predictors of dropout status" (p. 136).

McFarlane, Farley, Guerrero, and Galea'i (1996) also emphasize the importance of having staff members who can speak the native language of intended clients or consumers. They quote Vash (1994):

Language is a critical factor in understanding culture. When you try to understand and analyze beliefs, ethical values, and convictions, there are deep concepts that are very much tied to language. When you rely on translators, you lose a great deal. Individuals who can speak two languages are almost essential. (McFarlane et al., p. 23)

One strategy that has been used successfully in several contexts is training and employing paraprofessionals drawn from the client community (McFarlane & Fehir, 1994). D'Alonzo, Giordano, and Oyenque (1996) report on a rehabilitation services project in New Mexico which used

paraprofessionals drawn from local American Indian tribes to work with American Indian clients. Over a one-year period, the employment rate of American Indian rehabilitation clients more than doubled, from 14 percent to 31 percent, and the unsuccessful termination rate dropped by more than 20 percent. Locust and Lang (1996) report on a similar outreach effort with potential American Indian clients in Florida, a "Native American Technician" program in which "tribal people are employed via a subcontract with a tribe or tribal entity to provide outreach to American Indian people with disabilities" (p. 11). Via this program, the number of American Indian clients in Florida increased from only one to 260 over a four year period. Ultimately, however, as Schaller, Parker, and García (1998) point out, using paraprofessionals is an incomplete answer to the need for greater numbers of rehabilitation professionals from culturally diverse backgrounds.

Diversifying marketing and service strategies. Backer (1994) discusses "social marketing," a strategy drawn from corporate marketing concepts; he notes that "social marketing provides a management framework for systematic efforts to understand a target audience for change" (p. 17). He describes key elements as follows:

Audience segmentation, a key concept of social marketing, involves subdividing the targets (e.g., teachers in a large school district) into both "demographic" and "psychographic" groups, based on an understanding of what personal or group characteristics have a bearing on their behavior with respect to [adopting an innovation] . . . Learning what the individual differences are requires *audience analysis*, frequently using marketing techniques such as "focus groups." (p. 17)

Similarly, Yamashiro and Matsuoka (1997) describe the need for "culturally sensitive marketing strategies" for mental health service providers. Elements of such strategies, as they describe them, include:

- "removing impediments to services" by assuring procedures that address cultural needs, for example, confidentiality measures that families perceive will protect them from losing "face" (p. 183),
- adopting culturally inclusive perspectives on disability and dysfunction, and
- conducting research and needs assessments to "determine who the prospective clients are and where they reside," so that outreach efforts can be tailored to the concerns and needs of specific audiences (p. 184).

Schaller, Parker, and García (1998), among others, describe changes in practice that contribute to cultural competence. These include showing respect for cultural values and mores, addressing families as well as individual clients, locating services within the client community, assuring language accessibility via both print materials and interpreters, and using culturally sensitive assessment tools.

Issues in conducting research. Research organizations, of course, are not direct service providers. However, concerns for racial, ethnic, cultural, and linguistic diversity among staff, for understanding of cultural dynamics and the diversity between and within specific populations, and for a commitment to empowerment are all relevant to research as well as service agencies. In a research context, "empowerment" relates to the processes through which researchers determine the focus of research; the specific questions they pose; the ways in which they collect, organize, and analyze data; and the ways in which they attempt to get research outcomes into the hands of those who can use them. Wright and Leung (1993), among others, recommend that "minority communities and persons with disabilities should be involved in the process of planning research, implementing research, and interpreting findings of research" (n.p.). Without "cultural competence" as it is described above, research agencies will find it difficult to secure the involvement of minority groups in any meaningful way.

Some scholars concerned with diversity issues have focused a cultural lens specifically on the processes and assumptions of research. They have found "that data are collected, organized, and communicated within a cultural context and with tools that are also products of the culture" (Metoyer-Duran, 1991, p. 320). As Muntaner, Nieto, and O'Campo (1997) observe, the sociology and history of science show that:

Decisions about basic assumptions guiding research are social phenomena . . . The scientific community determines in part the acceptability of hypotheses for inquiry, publication, and continued funding through a social process in which certain assumptions are uncritically accepted even in the face of empirical refutation. (p. 263)

The following paragraphs describe some of the issues that have been raised in the literature. These range from overarching, epistemological concerns to specific methodological issues.

Epistemological issues. The examination of cultural beliefs extends not only to methodology, but to the epistemological foundations upon which research methods are constructed. For example, Scheurich and Young (1997) note "a lack of understanding among researchers as to how race is a critically significant epistemological problem in educational research" (p. 4). They point out that "no epistemology is context-free. Yet, all of the epistemologies currently legitimated in education arise exclusively out of the social history of the dominant White race . . . In other words, our 'logics of inquiry' (Stanfield, 1993) are the social products and practices of the social, historical experiences of Whites" (p. 8). Buchman (1982) discusses the fact that researchers and developers often fail to perceive the influence of their own theories and beliefs on the outcomes of their work; he quotes Nisbett and Ross (1980) regarding "the fallacy of misplaced certainty:"

An important step in reducing people's overconfidence would be taken by leading them to recognize that their interpretations of events, rather than being simple read-outs of data, are inferences that make heavy use of theory. Once one recognizes that the same data would look quite different, and could easily support different beliefs, if those data were viewed from the vantage point of alternative theories, the groundwork for a humbler epistemic stance has been laid. (p. 2)

Costa and Bamossy (1995; see also Taylor and Bogdan, 1984) describe common epistemological errors, describing many studies as "parochial," meaning that they "assume similarity" based on characteristics of one culture and pose that similarity as the norm. Costa and Bamossy also describe "ethnocentric research," in which "one culture's 'universal' theories are imposed on another culture;" in such studies, researchers explore differences, but those differences are examined and explained in reference to norms that are assumed to be universal. In contrast to these approaches, the authors recommend comparative studies, which "search for both similarities and differences" without presuming universal norms or the superiority of one set of cultural characteristics over another (p. 21).

Methodological issues. The literature identifies a host of methodological concerns that can compromise the reliability and validity of research outcomes. As discussed below, these include issues related to research design, sampling and other data collection procedures, and data analysis.

Research design. In spite of some researchers' continuing concerns about the validity and generalizability of qualitative research (Conwal Inc., n.d.), Taylor and Bogdan (1984), as well as others, suggest the strengths of qualitative or ethnographic research designs over the more commonly used positivist methodologies in exploring questions related to minority populations. For example, Harry (1992) in discussing studies of parents of children with disabilities, states that studies of parental attitudes "will be more reliable if they utilize a recursive, open-ended approach" (p. 103).

Hermes (1998) reflects one trend in qualitative research with minority groups. In her report on research with an Ojibwe Indian tribe, she describes an approach of "reciprocity and mutual respect" in which she sought guidance and feedback from the community she was studying at every step in her research, from identifying research questions to collecting, review, and analyzing data. Noting that her relationships with the community "ordered the methods" of her research, she recommends a "guiding principle:" "Be in the community as a member first and a researcher second" (p. 166).

Smart and Smart (1997) describe other research methodologies that appear to hold promise in "unraveling the complex relationship between social conditions and minority status" and assessing strategies for "treatment and prevention of disabilities in minority populations" (p. 12). Citing Adler et al. (1994), they report on promising research designs, including

Issues in conducting research. *continued*

the use of tree-structured regression and "grade of membership" analyses. Tree-structured regression techniques partition populations into subgroups and then identify different paths to given outcomes. Their strength lies in their ability to analyze numerous, complex, interrelated variables. Likewise, "grade of membership" analysis is able to accommodate larger numbers of variables by developing "ideal descriptions," either theoretically or empirically, of various classes of individuals. This technique becomes more precise with the addition of more and more variables. (p. 13)

Identifying and defining variables. Smart and Smart (1997) and others discuss the common problem of "inadequate definition of research variables" (pp. 32-33), particularly the "validity of racial/ethnic classification" (Duarte & Rice, 1992, p. 13, citing Kumanyika and Golden, 1991). Anderson, Wang, and Houser (1993) cite Hahn (1992), who "believes that the assessment of demographic identity in a society with a culturally diverse and rapidly changing population is extremely difficult." Hahn challenges "the assumption that categories of race and ethnicity are consistently defined when, in fact, terminology and categorization differ from source to source and region to region" (p. 12). Smart and Smart note, for example, that "many researchers have failed to distinguish the various subgroups of the Hispanic population, obscuring important differences between such groups . . . Different definitions of the terms 'Hispanic,' 'Latino,' and 'Mexican American' have yielded different samples, each with varying socio-demographic characteristics" (p. 33). Also challenged is the assumption "that the racial and ethnic categories used by researchers are adequately understood by those being surveyed" (Anderson, Wang, & Houser, p. 12).

Taylor and Bogdan (1984) discuss the problems that can arise when research variables are defined in rigid ways that cannot accommodate the realities of life among the populations studied. As an example, they describe a study that focused on conditions within "single-parent" vs. "dual-parent" homes. In collecting data, researchers found that those two categories failed to capture the variety of living arrangements that characterized most of the homes under study, for example, homes that included extended family members who filled parenting roles. However, because of the study's rigid design, researchers were forced to attempt to fit the data to their pre-existing categories.

Sampling and data collection procedures. As noted in the previous paragraph, sampling procedures can be compromised by poor definition of variables associated with the populations being sampled. In addition, a number of authors note that studies involving nonmainstream populations often rely on inadequate sample size (Anderson, Wang, & Houser, 1993; see also Duarte & Rice, 1992).

Concerns regarding data collection procedures include problems in accessing and obtaining data from a representative sample. Huff (1994), for example, describes the complexities involved in trying to set up a focus group composed of urban African American families: "We have learned that . . . families . . . may not have: (1) an address; (2) a telephone; (3) access to banking services; or (4) transportation" (p. 10). Anderson, Wang, and Houser (1993) conducted a needs survey among people with disabilities in Hawaii. Using a mail survey approach, they were unable to obtain an adequate return rate. They concluded that the return rate "may have been affected by the values and traditions within Asian cultures that emphasize the importance of keeping information about the family within its unit" (p. 14).

Researchers' failure to understand and accommodate cultural proprieties can result in the provision of misleading or inaccurate data. Harry (1992) notes that, "given all that is known about power relations between dominant and subordinate cultural groups, it should always be assumed that respondents' initial answers to judgments about the educational system may not be reliable" (p. 103). She quotes Leung (1988), who describes responses to research questions among Asian parents: "Attention and affirmation may only mean courtesy and propriety" (p. 105). Yu (1985, cited by Harry) refers to such patterns of response as "courtesy bias," "which may occur when informants do not yet trust the researcher and when researchers are not aware of the cultural inappropriateness of certain approaches" (Harry, p. 105). Problems also arise in assuring mutual understanding of terms used in survey questions. Taylor and Bogdan caution that "field researchers must start with the premise that words and symbols used in their own worlds may have different meanings in the worlds of their informants" (p. 51).

One major concern in data collection is the use of translators in obtaining data from non-English-speaking subjects. Smart and Smart (1992; see also Harry) describe the problems inherent in the common practice of using friends or other family members to act as interpreters, whether in a research or a service setting:

The use of family and friends as translators violates the right of privacy of the client . . . When the children of the client are used as translators, the client may be reluctant to fully discuss certain topics or the translator may have a tendency to speak for the client. Use of family members as interpreters alters the family structure. (p. 34)

As noted earlier, the use of interpreters also can result in the loss or misinterpretation of responses. The most effective data collection strategy is for those who conduct interviews, observations, or surveys to speak the respondents' language and to be well-oriented to the cultural context in which the research activity is being conducted. The same considerations should apply in settings requiring interpretation for persons who are deaf or hearing impaired.

Data analysis. Two criticisms of data analysis appear most consistently in the literature. The first is misinterpretation based on a lack of cultural understandings or the assumption of normative standards that are, in fact, culturally derived (Duarte & Rice, 1992; Harry 1992). The second is the common failure to account for "within-group differences" when reporting on particular populations. Studies suggest that analyses of racial and ethnic demographics often overemphasize between-group differences and under-emphasize within-group differences, so that differences between groups may be exaggerated, while differences within a specific group may be overlooked (Anderson, Wang, & Houser, 1993; NCDDR, 1996).

Issues in dissemination and utilization.

Although information is limited regarding dissemination and utilization (D&U) strategies targeted specifically to minority populations, there is a considerable literature base describing D&U processes in general. Experts now understand knowledge utilization as a *learning* process in which the potential user, or consumer, is "an active problem-solver and a constructor of his or her own knowledge," not merely "a passive receptacle of information and expertise," as earlier D&U theories had suggested (Hutchinson & Huberman, 1993, p. 2). Knowledge is no longer thought of as an inert object to be "sent" and "received," but rather as a fluid set of understandings that are shaped by those who use it as well as by those who originate it (NCDDR, 1996).

The relationships between the potential *user* and the D&U *source, content, context, and media* used are critical determinants of effectiveness, with attention to particular user groups as the most central concern. Findings related to the D&U process that have appeared to have particular implications for work with minority persons with disabilities and their families are outlined below.

Credibility and trust. Potential users of research outcomes tend to accept assistance, information, and ideas from sources they know and trust (Carrillo, Lumbley, & Westbrook, 1990; Fullan, 1991; Robinault, Weisinger, & Folsom, 1980). Users tend to be more concerned about the source of the information that is disseminated than about the specific content of the information (Hutchinson & Huberman). Some studies suggest that the source's perceived expertise is less important to users than trustworthiness in obtaining user support (Marquart, O'Keefe, & Gunther, 1995). Given the findings regarding cultural mistrust (discussed in Volume 4, Number 1, page 9: Inequities and the rehabilitation system), the importance of establishing credibility and trust with minority populations cannot be overemphasized. And cultural responsiveness is essential to establishing such confidence (Schaller, Parker, & García, 1998).

Utility. If research outcomes are to be used, they must be perceived by potential users as relevant to their needs and daily lives. Dentler (1984), among others, stresses that "the property of knowledge that is essential for [use] is its congruence with the real world of practice" (n.p.). Similarly, a study

of Tennessee school systems reported by West and Rhoton (1992) concludes that "the strongest barrier to research utilization statewide was the [perceived] non-practical focus of research reports" (p. 13). For effective D&U, then, researchers must know a great deal about the priorities, needs, environments, and circumstances of their intended users, and must tailor their outcomes and information accordingly.

Cultural responsiveness. To be effective, D&U strategies must be appropriate within potential users' cultural contexts (Duarte & Rice, 1992). This includes understanding and addressing users' perceptions about disability, family, and propriety. Information about research outcomes also must be easily understandable by potential users. Leung (1992), for example, reports that "language differences" are a primary cause of negative attitudes about researchers—not only in terms of English vs. other languages, but in terms of dense, technical descriptions that assume a vocabulary and contextual knowledge most nonresearchers do not possess.

It is also critical to know what dissemination channels are available to, and used by, potential user groups (Edwards, 1991). Leung (1992) notes that one of the most elementary—and important—guidelines for selecting a dissemination medium is that "utilization will not occur if persons with disabilities cannot physically gain access" (p. 299).

Personal contact. Perhaps the most consistent finding in the literature on knowledge utilization is the importance of personal contact for the success of dissemination activities. As Fullan (1991) notes, "The primacy of personal contact in the diffusion of innovations has been known for years" (p. 53). This finding has significant implications for D&U activities targeted to minority populations. To provide for personal contact with potential users, most research agencies must rely on intermediaries. However, relying solely or primarily on intermediaries from government agencies and service providers within the rehabilitation system is likely to prove inadequate. Many people who are oriented to traditional minority cultures tend to seek help outside the established rehabilitation and medical systems, and it is important for researchers to broaden their contact to include these community resources, including, among others, community agencies and organizations, informal community leaders, church personnel, and healers (Schensul, 1992). In addition, persons from lower socioeconomic brackets—who are disproportionately from minority populations—often require special outreach efforts due to their lack of access to mainstream services and resources.

D&U research findings targeted specifically to minority populations. As noted earlier, the research literature contains limited information regarding dissemination media and methods that have proven effective with specific minority populations. However, a few studies exist that suggest promising strategies, at least within the limited contexts studied:

Issues in dissemination and utilization.

continued

- Metoyer-Duran (1991, 1993) has conducted studies suggesting that "ethnolinguistic gatekeepers" within traditional cultural communities serve as "information and referral agents" (1993, p. 365). Her research suggests "that gatekeepers have greater awareness of and use more information resources than other community members, even when controlling for educational level, employment status, income, and longevity in the community" (1991, p. 325). Metoyer-Duran found that these gatekeepers draw on a number of information sources, including mass media, print, and institutional representatives. However, they are most likely to consult interpersonal sources. To access gatekeepers as potential dissemination channels, she recommends "establishing close relationships with other institutional sources used by gatekeepers" (1993, p. 368).
- Schensul (1992) and colleagues conducted research to help identify dissemination strategies that could effectively deliver information about Alzheimer's disease to elderly Latinos in the U.S.. Among the strategies they tried were presentations in churches, pamphlets left in churches, a community conference, an art exhibit of "symptom depiction cards" drawn by "a well-known Puerto Rican artist" (p. 21), contact with informal building leaders, botánicas, Spanish radio, Spanish and English neighborhood newspapers, and community outreach via service providers. They found that, of the public media they tried, Spanish radio proved the most effective dissemination channel. The authors found "that most Latino elderly prefer listening to one or two specific stations, and do so regularly throughout the day." The authors recommend appearances on radio call-in shows over the more commonly used Public Service Announcements (PSAs), noting that PSAs "hold limited attention and come on infrequently. More effective are call-in shows, especially those focused on the general problems of Latino elderly . . . The Spanish language call-in show is an extremely important untapped venue for dissemination of health-related information because it is interactive" (p. 23). Regarding the effectiveness of Spanish language newspapers, the study found that they were "widely read, but when questioned, readers did not mention knowledge of Alzheimer's Disease or its management" (p. 23).
- Schensul also reports that, because elderly Latinos tend to fear the diagnosis of Alzheimer's disease, standard presentations on the disease that include discussions of etiology, symptoms, natural history and management, "will not be received and may in fact reduce the likelihood that seniors and their families will report symptoms to a physician. Any technique which uses informal dialogue about daily or historical aspects of participants' lives will be more successful in opening the door to 'discovering' dementia" (p. 26).
- Ward et al. (1993) describe a study of targeted media campaigns designed to address the underutilization by racial and ethnic minorities of a telephone-based cancer information service. They found that, among all audience groups, television was the most effective medium in increasing the number of telephone inquiries. However, they also found that the effects of the special promotional campaigns, whether via television or other media, tended to be short term.
- Online technologies represent an increasingly important dissemination strategy, but many people still lack access. Although some studies suggest that racial differences in computer and Internet use are shrinking in the U.S., differences persist. Wilhelm (1996), for example, reports on computer use among Latinos in the U.S. and notes that "civic networking" via the Internet "is evolving into an important public space" via networks such as LatinoNet and ChicanoNet. However, even after controlling for variables such as income and education, "Latinos still experience lower levels of computer access than do non-Latinos" (p. 23). In another report, Wilhelm (1995) notes that "overall, there are still 4.4 million households in the U.S. that go without a phone. Among Latinos, 13.3 percent of all households function without immediate access to a telephone" (p. 3).

Conclusions and recommendations

The larger literature on knowledge utilization indicates that, to be effective, dissemination and utilization cannot be "tag-on" activities. Rather, D&U concerns must be incorporated into the earliest planning stages of a research study (NCDDR, 1996). The D&U literature also indicates that, when potential users assess information about research outcomes, the credibility and perceived trustworthiness of the source is of paramount importance—and, as the literature on diversity suggests, trustworthiness relates to the capacity to be culturally responsive. The work of increasing the use of research outcomes among diverse consumer populations, then, lies not merely in selecting dissemination media or packaging information to be distributed via those media. The overarching task lies in becoming a "culturally competent" organization, one that knows, listens to, works with, and addresses the needs of its intended audiences; one that reflects the diversity of those audiences in its policies and personnel; and one that involves potential users throughout the research, development, and dissemination process.

The following are some suggestions for working toward cultural competence in terms of organizational structure and policies, research activities, and dissemination and utilization

activities. Because little research exists that addresses the processes of dissemination and utilization for minority persons with disabilities, these recommendations must be considered tentative; they are based on a synthesis of understandings about knowledge utilization, on the one hand, and about racial, ethnic, and cultural diversity on the other.

Organizational recommendations

- Review and adapt organizational purposes and policies to include a commitment to cultural competence. Make this commitment pervasive and long term.
- Examine recruitment and hiring policies and procedures. Look for the cultural assumptions contained within them and consider the effects of those assumptions on the organization's staffing choices. Seek ways of diversifying staff. Avoid tokenism.
- Make sure all staff understand that cultural competence is the responsibility of the entire organization, not only of minority staff members or "special" projects or committees.
- Seek ways of establishing an active, partnering presence within the community, whether "community" is defined by geography or interest.
- Build strong, ongoing relationships with a wide variety of intermediaries who have direct access to potential users. Approach these relationships as a partner rather than as a provider. Remember that intermediaries, like targeted users, will need to find the organization, its activities, and its outcomes both relevant and trustworthy.
- Structure data collection activities to assure an appropriate rate of return from all targeted subpopulations. This likely will require a variety of data collection activities that extend beyond traditional mail or telephone surveys, particularly to reach low-income respondents. Take care to assure that interview and other questioning techniques are culturally appropriate. Assure language accessibility via both print and interpreters.
- In analyzing data, carefully consider within-group as well as between-group differences. Be cautious of making cultural assumptions in data analysis and conclusions.
- Seek input and feedback—eliciting both formal and informal "reality checks"—from representatives of target audiences in identifying data collection procedures, identifying or developing data collection instruments, analyzing data, and drawing conclusions.

Dissemination and utilization recommendations

Research recommendations

- Ground decisions about research purposes and hypotheses in a thorough knowledge of potential user audiences. Employ a variety of methods to learn about those audiences, including focus groups, surveys, community involvement, input from intermediaries, and ongoing input from potential users themselves.
- Examine the assumptions inherent in the goals, hypotheses, and methods of the intended research. Ask others to explore those assumptions, particularly people with experience and insight into potential user groups, and representatives from those groups.
- Explore a variety of research methodologies, seeking to identify approaches that are most likely to yield accurate, in-depth outcomes related to all target audiences. Consider a blend of qualitative and quantitative approaches.
- Define all variables fully; be cautious about hidden assumptions and/or comparisons with variables in other studies that may be differently or less fully defined.
- Use sampling techniques that provide for adequate representation among all targeted audiences, and address appropriate subpopulations, not merely broad racial or ethnic categories.
- Begin thinking about the task of dissemination and utilization at the earliest stages of the research effort.
- In learning about potential user groups (see recommendation, above), seek to identify the information sources and media on which they most frequently rely. Consider not only traditional media, such as print and television, but community resources, leaders, and informal "gatekeepers."
- Use multiple dissemination strategies and media, targeted to specific subpopulations. Never rely on a single approach.
- In determining what information to disseminate, consider what the potential user will think is important. Labels, titles, and supporting data that are important to funding sources and other researchers often seem completely irrelevant to intermediaries, potential consumers, and their families.
- Assure that the information to be disseminated is accessible in language, syntax, format, and length; respectful of cultural customs and proprieties; and relevant to potential users' concerns.
- Draw as extensively as possible on D&U strategies that provide for personal contact between potential users and persons who can facilitate the use of research outcomes. Use intermediaries: service providers such as independent living centers or rehabilitation service agencies; community resources such as advocacy groups, churches, community centers, and the like; and informal community leaders and resources, including herbalists and healers who apply traditional cultural approaches. Remember that using intermediaries means the intermediaries themselves become a D&U audience.
- Seek input and feedback from representatives of target audiences throughout the D&U process.



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Dr. Vinton Cerf Visits NIDRR

Dr. Vinton Cerf, often credited as the "Father of the Internet," visited the National Institute on Disability and Rehabilitation Research on March 30, 1999. At the invitation of NIDRR Director Dr. Katherine D. Seelman, Dr. Cerf gave an informative presentation on the history and scope of the Internet to invited guests from throughout the Government and private disability organizations. NIDRR staff also shared some of the goals and achievements of NIDRR-funded research with Dr. Cerf and the audience.

Dr. Cerf began with a number of quotations that reflected the uncertain future that great leaders had foreseen for various communication modes over the years, such as the telephone and the computer. Ironically, all of the views of these early pioneers or observers of the information scene have proven to be overtaken by their great convenience and widespread use. Even Dr. Cerf, in spite of his gift for envisioning the Internet, seriously underestimated the dimensions of memory that would be needed to engage in the kinds of information and commerce that have developed through the Internet of today.

That growth has been phenomenal. Dr. Cerf pointed out that the Internet as we now know and "love" it is a relative newcomer to the communications scene. It began as an idea in 1974, moved to the research and development stage at the Defense Advanced Research Projects Agency (DARPA) in 1983,

with no concept of its present rapid growth and expansion. As difficult as it may be to believe, as late as 1990 there were no commercial services on the "Net."

Internet use is growing by leaps and bounds—100% per year. There are more than 50 million computers on the Internet today. Some forty percent of American homes currently have access with the number growing daily. Sixty percent of homes with children have online access. Dr. Cerf predicts that by the year 2006, the Internet will be the size of the telephone system and it will be the dominant communication system of the 21st century.

Dr. Cerf says that there are three million Web sites and some 700 million pages on the World Wide Web. Of particular interest to us in the disability field is the fact that most of these pages are not and will not be accessible, nor will they be retrofitted to become accessible. Even if page designers were made fully aware of the need for the accessibility of Web pages for people with disabilities, this does not address the growing complexity of multicasting and other elements which are becoming commonplace on the Internet. There is much work to be done to publicize accessibility.

In addition, Dr. Cerf suggests that the best hope of surmounting the problem is to devise tools that will make accessibility almost automatic. Dr. Cerf stressed the importance of finding economic advantages that can be brought to the attention of business and industry that would make them see the wisdom of partnering to produce and use such tools.

While "distance learning" holds promise for persons with disabilities to increase their training and education without physical access to sites of learning, Dr. Cerf predicts that the technology needed for optimal two-way communication over the Internet is not likely to arrive soon. Even current on-screen use of American Sign Language (ASL) is not smooth, given the bandwidth necessary for two-way transfer of photos and dialogue.

The Internet is becoming a major vehicle for the trading of goods and services, and will continue to expand in this vein. While the Internet accounts for about one percent of trade in the United States today, Dr. Cerf predicts this will grow to about ten percent by 2003. Persons with disabilities are potential customers for this market; in fact, it may be that the ease of shopping on the Internet, paying bills, voting corporate shares by proxy and other services, have true appeal for them. Just as the disability community is making itself known as a considerable voting entity, it might be useful to remind business of its growing stature as a buying public, especially with its potential growth encompassing aging members of the "Baby Boom" generation. Dr. Cerf also acknowledged the expansion of Kaleidoscope, a television network focusing on people with disabilities, to encompass many media and to provide specialized programming.

Dr. Cerf has personal experience with hearing loss and—on the part of his wife—cochlear implants, and he fully

Other References

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acknowledges the power of the technological interface between electronic systems and the body. The potential for remarkable research in sensory and neural processing with electronic assistance provides hope for such things as artificial retinas and such processes as Functional Electronic Stimulation (FES), which NIDRR has funded for many years as a potential rehabilitation technique.

Recognizing the impact of the Internet on medical practice, with both the better dissemination of information to clients and the increased access of physicians to information, Dr. Cerf expressed some concern that too much regulation of the Internet poses potential problems. He said that once the Internet becomes a part of the infrastructure, there are needs for policy protocols, but there must not be an overreaction leading to massive restriction of its freedom. His recommendation was that we seek ways to attract business as well as Government to the development and policy processes.

The speaker was asked about the hopes for simplifying the features of Internet software for persons with cognitive disabilities. The World Wide Web Consortium (W3C) is working on making the Internet accessible and a member of the Web Accessibility Initiative (WAI) shared with the audience the progress that group is making. Dr. Cerf explained that we are in a most creative period for the Internet due to its exponential growth, and that within this period, it is possible that standardization can be achieved first and simplification will follow.

Dr. Cerf represents to NIDRR an example of the great accomplishments of the creative minds of the 20th century as well as the promise for conjoined thought and action in the 21st century. NIDRR is grateful for Dr. Cerf's visit and hopes that this is just the beginning of "a beautiful friendship."

NIDRR Staff Share Information with Dr. Cerf

NIDRR staff members discussed current activities that are compatible with Dr. Cerf's view of the future. For example, to encourage the "mainstreaming" of persons with disabilities into the larger society, NIDRR supports a range of engineering research which has expanded to encompass medical technology, technology for increased function, and "systems technology."

NIDRR's technology program espouses the ideas made popular by the late Ron Mace for the building of a society that considers the lifespan needs of individuals and builds environments where all people can move easily from one activity to another. The NIDRR-funded Rehabilitation Engineering Research Center (RERC) at North Carolina State University is the leading research center in the nation promoting this concept of universal design.

NIDRR has sponsored cutting-edge programs at the National Center for Accessible Media (NCAM) at WBGH in Boston. It funded the Center's earliest work on captioning, which proved that technology designed for a disability sector (persons who are deaf or hearing-impaired) can be readily

useful to other persons and settings (where a TV picture is on but sound is turned off, such as gyms, busy social halls, and bars). NIDRR has sponsored Motion Picture Access I and II, and is currently funding stage III for the realization of commercial movie access for people who are deaf. A NIDRR-sponsored Field-Initiated project is investigating the meaning of the newest technologies such as DVD add-ons to the Internet and what this means for persons with disabilities.

Similarly, NIDRR has long been interested and engaged in questions of telecommunications accessibility and policy. The Trace Center at the University of Wisconsin-Madison has been a forerunner in working with the commercial sector to incorporate universal design in televisions and to build-in software access at the beginning of the process, including Windows 95.

NIDRR is involved in "distance learning" projects to help provide educational access to persons with disabilities in their communities, including rural settings where accessible institutions and experienced personnel are in short supply. NIDRR has also funded Field-Initiated research to test methods of representing American Sign Language (ASL) in video form on the Internet or CD-ROM. A major new RERC in Telerehabilitation was funded by NIDRR on the heels of a Fellowship and a Field-Initiated Project.

Regarding the orphan technology problem and the transfer of technological devices to larger markets, the NIDRR-funded RERC on Technology Transfer at SUNY Buffalo helps small technology developers and entrepreneurs to interest larger manufacturers to produce their products or to find capital needed to increase the production and spread of these devices.

In the realm of bioengineering, NIDRR has been a significant partner in research into cutting-edge technologies for prosthetics and orthotics, wheelchairs, controls, communication devices, Functional Electrical Stimulation (FES), FM listening systems, hearing aid technology and a host of other research endeavors.

Not only in research, but also in public awareness and access to assistive devices, NIDRR has established programs to spread technology. The Assistive Technology Act of 1998 is only the latest legislative-based program to assist the technology field. Programs in all 50 states and the territories take technology to where people live. NIDRR's efforts help people learn about products through ABLEDATA and other information systems, and helps them to find and fund assistive devices. The Disability and Business Technical Assistance Centers program (DBTACs) reinforces the ideals of the Americans with Disabilities Act and helps to make adapted living, employment, transportation, housing and the ultimate goal of universal design, a real possibility.

Ellen Blasiotti, NIDRR



NOTICE

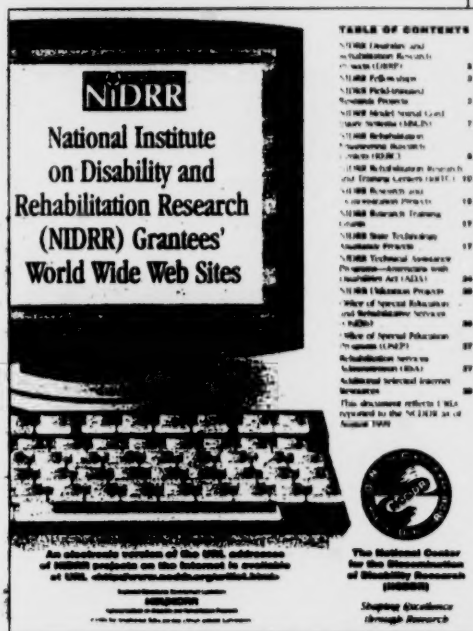
for NIDRR Grantees

In 1997 and 1998, one of the most-requested products from the NCDDR was the paper version of the listing of **NIDRR Grantees' World Wide Web sites**. NCDDR staff are now updating this document for the third time, for planned publication in August, 1999. All NIDRR grantees have been asked on several occasions to give their Web site addresses and updates when changes are made, so that we can maintain an up-to-date listing.

Please visit the NCDDR Web site's **NIDRR Projects on the Internet** at <http://www.ncddr.org/urllist.html> and verify that the **Project Name, URL, mailing address, and telephone number(s)** listed for your NIDRR-funded project are accurate. The listing is by type of project, and projects are listed alphabetically within each category. If there are errors, or your project does not appear but it does have a Web site, we would appreciate it if the PI or Contact Person would get in touch with NCDDR staff so that we can include your information, both on our Web site and in the upcoming booklet.

Contact the NCDDR:

Toll-free: 800-266-1832 (Mon.-Fri., 8:00 AM - 5:00 PM, Central Time)
By e-mail: admin@ncddr.org
By Fax: 512-476-2286
By U.S. Mail: NCDDR/SEDL
 211 E. 7th St., Suite 400
 Austin, TX 78701-3281



NIDRR Grantees Receive Recognition

The NCDDR congratulates each of the following NIDRR grantees and staff members. All grantees are encouraged to contact the NCDDR with information to share in future issues of *The Research Exchange*.

Katherine D. Seelman, Ph.D., Director of the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services in the U.S. Department of Education, has been named a Fellow of the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA). The award was presented at RESNA's Annual Conference on Tuesday, June 28, 1999, in Long Beach, California.

Dr. Seelman, Director of NIDRR since 1995, was cited by RESNA for her commitment in developing the fields of assistive technology and rehabilitation engineering. This award, the engineering society's highest honor, specifically recognizes **Dr. Seelman's** "consistent leadership and vision on behalf of persons with disabilities and the possibilities offered them through the use of technology."

She joins a group of distinguished fellows and honorary fellows, including well-known scientists and leaders in rehabilitation engineering such as: **Dr. Dudley Childress** (Northwestern University), **Dr. Lawrence Scadden** (National Science Foundation), **Dr. Gregg Vanderheiden** (University of Wisconsin-Madison), the **Hon. Tom Harkin** (United States Senate), and (posthumously) **Mr. Ed Roberts** (World Institute on Disability).

Dr. Seelman is chair of the Interagency Committee on Disability Research (ICDR), and she has been Co-Chair of major U.S. and international delegations in disability research and science. She also has been the recipient of a distinguished Switzer fellowship, a National Science Foundation Assistantship and she is a member of the Hunter College Hall of Fame.

Dr. Seelman also accepted the Association of Access Engineering Specialists (AAES) *Excellence in Access* award on behalf of the Department of Education. The Department's OCIO Assistive Technology Team won the award for their implementation of the "Requirements for Accessible Software Design."

For further information contact **Ellen Blasiotti** at NIDRR: ellen_blasotti@ed.gov

Dr. Megan Kirshbaum, Project Co-Director, **National Resource Center for Parents with Disabilities** at Through the Looking Glass, Berkeley, CA, was selected for a two-year fellowship in ZERO TO THREE's prestigious *Leaders for the 21st Century* program. One of 15 Mid-Career Fellows, **Dr. Kirshbaum's** project will evaluate assessments of parents with cognitive disabilities who are involved with children's

protective services departments nationally, and propose guidelines for appropriate practice. ZERO TO THREE is a national, nonprofit organization dedicated to advancing the healthy development of babies and young children. *Leaders for the 21st Century* is funded by grants from the Robert Wood Johnson Foundation and philanthropist Irving Harris.

Judith Rogers, OTR, Pregnancy and Birthing Specialist at the **National Resource Center**, was honored by the Alta Bates Hospital and Breast Cancer Fund for her community advocacy leading to the establishment of a breast cancer prevention center for women with disabilities. For further information contact **Dr. Kirshbaum** and **Ms. Rogers** at (800) 644-2666 or by e-mail: megan_kirshbaum@lookingglass.org and judi_rogers@lookingglass.org

Dr. Charlie Lakin, Principal Investigator of the **Research and Training Center on Community Living** at the University of Minnesota's Institute on Community Integration, received the *Dybwad Humanitarian Award*. It was presented at the American Association on Mental Retardation's 123rd Annual Conference on May 22, 1999, in New Orleans. The *Dybwad Humanitarian Award* was made to **Dr. Lakin** "for promotion of human welfare and social reform." For further information contact **Dr. Lakin** at (612) 624-5005 or by e-mail: lakin001@umn.edu

NIDRR-related Web sites win awards

- Macro International's **ABLEDATA** Web site at <http://www.abledata.com/> was selected in November, 1998 to receive a *Links2Go Key Resource* award in the Disabilities topic. Links2Go selects at most 50 of the most representative links as the "Key Resources" for each topic, based on an analysis of millions of Web pages. Please visit <http://www.links2go.com/award/Disabilities> for more information, or contact Assistant Project Director **Katherine Belknap** at (301) 608-8998 x 100 or by e-mail at: belknap@macroint.com
 - The Rehabilitation Robotics Research Program's World Wide Web site <http://www.asel.udel.edu/robotics/> was chosen by BioMedLink as a "three star 'indispensable' site" in January 1998. <http://www.biomednet.com/db/biomedlink/BMLK.12558> BioMedLink is an evaluated and annotated database of Internet resources for biological and medical researchers and is part of BioMedNet.
- The Web site was also chosen as a "Web Pick" by the HMS Beagle BioMedNet Magazine. <http://www.biomednet.com/hmsbeagle/44/webres/webpick.htm>
- The **RERC on Rehabilitation Robotics** is part of the Robotics Research Program at the University of Delaware. For more information, contact **Dr. Richard A. Foulds**, Principal Investigator of the **RERC**, at (302) 651-6830 or by e-mail: foulds@asel.udel.edu

- **Speaking to Write: Realizing the Potential of Speech Recognition for Secondary Students with Disabilities** is a field-initiated project of the Education Development Center, Inc. (EDC) and the Communication Enhancement Center at Children's Hospital, Boston. **Dr. Patricia Corley** of EDC is Principal Investigator. The project's Web site was awarded a "B" by Education World's *Education Site Reviews* in June, 1998. <http://www.education-world.com/awards/past/r0698-18.shtml> Education World is designed to be a resource guide for educators and is produced by Concourse C, Inc. Digital Marketing Services, Oklahoma City. For more information, contact **Ms. Jennifer Gold** at (617) 969-7100 ext. 2485 or by email: jgold@edc.org

- Four NIDRR-related Web sites have been recognized as *Picks of the Month* by the U.S. Department of Education. <http://www.ed.gov/Picks/> ED picks three great resources every month and highlights them on the ED Web site. The picks are taken from three broad categories: ED-affiliated Internet sites elsewhere, newly available documents of merit, and new selections at the ED site focusing on individual programs and offices. NIDRR-related *Picks of the Month* include:

NCDDR <http://www.ncddr.org/> (September, 1998)

NCAM <http://www.wgbh.org/ncam/> (November, 1997)

NIDRR <http://www.ed.gov/offices/OSERS/NIDRR/> (December, 1996)

NARIC <http://www.naric.com/> (December, 1995)

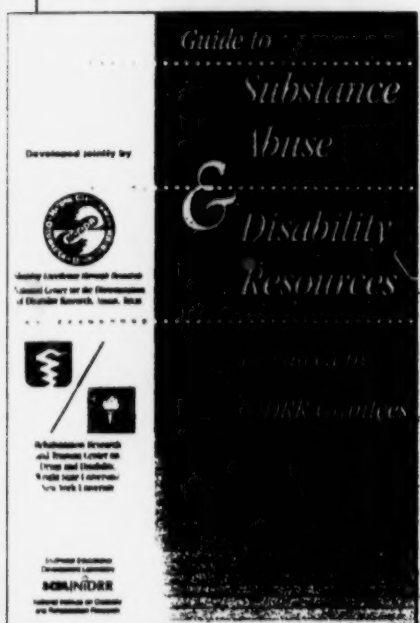
As the National Center for the Dissemination of Disability Research (NCDDR) looks toward the completion of a four-year pilot period, we would like to encourage all grantees to submit to us any special recognition made to NIDRR-funded projects or their staff members. This information will be compiled with past awards and recognition to demonstrate the achievements of NIDRR grantees over the past few years.

The NCDDR also wants to remind grantees to visit the *Calendar of NIDRR Project Events* at <http://www.ncddr.org/calendar/calendar.cgi> and use the online form to add new entries to the variety of events carried out by grantees. The form is at <http://www.ncddr.org/calendar/calendar.cgi?eregister.html> If preferred, an "Event Information" form is available in alternate formats.

A postage-paid return card is inserted with this issue for reporting recognition or calendar items or, contact the NCDDR to request a "NIDRR Grantee Recognition" or "Event Information" form by fax, email, or U.S. mail.



New Resource Highlighting Outcomes



The NCDDR and the Rehabilitation Research and Training Center on Drugs and Disability (Wright State University/ New York State University) have jointly developed a **Guide to Substance Abuse and Disability Resources** Produced by NIDRR Grantees.

The NCDDR contacted a large number of NIDRR Grantees most likely to have

produced research information concerning drug and alcohol abuse relating to their research topic, including mental health, brain injury, spinal cord injury, and other areas. The resulting *Guide* includes 109 items that are identified according to product type, subject terms co-existing with substance abuse, and by grantee.

The *Guide* is intended to be a resource for use by researchers, professionals and people with disabilities. It contains scholarly items as well as a number of immediately functional resources for use by teachers, rehabilitation personnel and others in their work with substance abuse issues. The *Guide* serves as a link between research and practice by providing readers with a basic description of available items and how to obtain the items directly from NIDRR grantees, or from the National Rehabilitation Information Center (NARIC). It is hoped that the *Guide* will serve as a model for similar collaborations with NIDRR Grantees on additional topics.

To date the *Guide* has been distributed to NIDRR Grantees, state directors of general and blind vocational rehabilitation services, selected members of the U.S. Congress, state directors of mental health services, state directors of special education, and administrators of Centers for Independent Living across the United States. A limited number of additional copies of the **Guide to Substance Abuse and Disability Resources Produced by NIDRR Grantees** are available from the NCDDR upon request. An online version of the *Guide* is available at <http://www.ncddr.org/du/saguide/>

How To Contact The National Center For The Dissemination Of Disability Research



Call Us

1-800-266-1832 or 512-476-6861 V/TT
8 A.M.-NOON and 1 P.M.-5 P.M. C.T. Mon.-Fri.
(except holidays) or record
a message 24 hr./day



Explore Our Web Site

<http://www.ncddr.org/>

E-mail Us

admin@ncddr.org



Write Us

National Center for the
Dissemination of Disability Research
Southwest Educational Development Laboratory
211 East Seventh Street, Suite 400
Austin, Texas 78701-3281



Visit Us

In downtown Austin, Texas 4th floor,
Southwest Tower, Brazos at 7th St.
8 A.M.-NOON and 1 P.M.-5 P.M. C.T.
Mon.-Fri. (except holidays)



Fax Us

512-476-2286

Southwest Educational Development Laboratory

SEDL/NIDRR

National Institute on Disability and Rehabilitation Research



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The Research Exchange is available in alternate formats upon request.

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A WORD FROM THE DIRECTOR

Expanding Our Dissemination Options

Your likelihood of being effective in meeting your dissemination goals may rest upon your ability to simultaneously manage a variety of dissemination options. We readily recognize that the audiences we target to use our grant-related information is highly varied. Too often, however, our selection of dissemination strategies is made as if this diversity does not exist.

continued on page 2

Disability Research and the Media



The limited presence of disability and rehabilitation research information reflects common practices of today's media. When people with disabilities or disability issues are portrayed in the popular media it is often with a sense of heroism (mountain climbers), charity and pity (telethons), or sensationalism (as in the *60 Minutes* video of Dr. Kevorkian and Mr. Thomas Youk, a man with ALS). When research information is presented it may be controversial (cloning), unique (Viagra research) or relevant to a large sector of society (breast cancer, heart disease, etc.). People with disabilities are regarded by the popular media as a somewhat invisible minority, and their concerns ongoing and largely unsensational. Therefore, disability and rehabilitation research seldom appear in the popular media.

Even in the disability media, when research information is provided it is usually in the form of a story about medical research, a research program, or as supporting information for a human-interest oriented story, such as unemployment levels among people with disabilities. This may not be surprising given the pragmatic viewpoints of the disability media on disability issues and lifestyles, plus their emulation of the popular press in requiring that information be current and newsworthy.

Expanding Our Dissemination Options

continued from page 1

University-based researchers continue to value the publication of articles in peer-reviewed journals. Within the university setting this type of publication is most easily rewarded and recognized by the peer group. The NCDDR recognizes great value in this type of documentation and publication of research-related information attendant to NIDRR grant activities. This issue of *The Research Exchange* looks at some issues related to journal article publication and suggests some considerations and resources that may assist grantees in this effort.

While publication in scholarly journals is important, it is also important for grantees to consider publication options within the disability and mainstream media outlets. How to develop the best press releases and how to "package" research-related information in formats such as press kits is addressed in this issue.

Information collected by the NCDDR tends to indicate that the overall number of journal article publications and media "stories" based on or alluding to NIDRR grant activity is increasing. These are very positive indications of the increasing attention to dissemination and utilization outcomes on the part of NIDRR's grantees. The use of electronic forms of distribution such as World Wide Web sites are increasing, to include approximately 80 percent of all NIDRR's grantees.

If it is true that the key to effective dissemination rests in the variety of appropriate options we use to communicate with diverse audiences, the trends demonstrated by NIDRR grantees indicate significant progress. As we move together toward a new millennium, the NCDDR staff look forward to working with grantees to meet the challenge of new and expanded dissemination options, innovations, and expectations.

John D. Westbrook, Ph.D.
Director, NCDDR



Disability Research and the Media

continued from page 1

Advances in Communication and Collaboration

One of the most important human innovations in the new millennium will be the increasing speed of information transfer. Current and emerging electronic media allow pictures, stories, ideas and facts to be transferred around the globe in immediate "real time." This quest for speed reduces dependency on traditional print media (Walker, 1999) and may one day replace traditional means of disseminating research information. The days of going to an information source such as a library to search through pertinent journals and review relevant articles, are quickly being replaced by Internet searches, online fact sheets, downloads of research information, and even email correspondence with researchers. In essence, innovations in information

transfer are bringing researchers and their research information closer to stakeholders who will ultimately utilize the research information.

In the areas of disability services, advocacy, and lifestyles, the traditional lag between research and practice is also diminishing. Formerly, researchers conducted controlled studies of innovative practices or social phenomena that had intended eventual impacts on people with disabilities. Researchers stood in the forefront of innovations in educational practices, community living, supported employment, behavior management, and other fields. With today's advocacy and empowerment, customer-driven practices may precede research, and the evolving role of research may be to validate or dispute, rather than create, innovation.

These factors provide implications for closing the communication gap between researchers and research information users, and for expanding the range of users beyond professionals and service providers to disability

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**An electronic version of
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<<http://www.ncddr.org/researchexchange/>>

**The Research Exchange is available in
alternate formats upon request.**

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groups and individuals with disabilities. Such prospects provide opportunities for researchers to develop timely research information by quantifying outcomes, introducing or reinforcing adaptations to service strategies, or providing informational forums for people planning to replicate practices. People with disabilities and researchers need to continue to develop close partnerships in mutual research and services to advance the objectives of all stakeholders.

The addition of people with disabilities as users of research information requires that the information be available in media sources and formats that are accessed by people with disabilities. The issues addressed by these media, such as enforcement of the Americans with Disabilities Act of 1990 (ADA), the Medicaid Community Attendant Services and Supports Act (MiCASSA) (Kafka, 1999), institutions vs. community services, changes in Social Security, and health care coverage, among others, are increasingly ripe areas for research to support customer-driven efforts toward change. These factors indicate that researchers should emphasize dissemination of their research information to disability media sources and the popular media.

Making Disability and Rehabilitation Research Information Newsworthy

In adopting press relations strategies, researchers may find that their research information is newsworthy enough for publication in both the popular and disability media. This is particularly true in cases where research information supports high-profile disability issues and events.

When the media consider whether a story is newsworthy they use the following three criteria:

1. The story will interest many readers and viewers,
2. It will interest typical readers,
3. The story is important to the lives of readers and viewers.

(Hartman & Johnson, 1993, p. 4).

If research information is particularly strong in one of these criteria, such as

interest to many readers and viewers, it may receive notice by the media. To accomplish "newsworthiness" researchers should attend to the following concerns in developing research information for the disability and popular media.

Putting on a "Human Face."

Research information, data and analyses may be considered newsworthy when placed in a framework of interesting stories about persons who are positively impacted by the research. The individual or "human face" presented should be representative of research issues and strategies. The story should result in gains for people with disabilities and increased understanding of their concerns. Researchers should refrain from portraying individuals in the context of overcoming their disability, or being overwhelmed by it (Hartman & Johnson, 1993). By providing factual personal accounts that are consistent with the research information, the readers' attention will not be diverted from the larger research issues and strategies.

Who Should Research Information Affect?

Most people in the media, and in the general public, either experience disabilities or have relatives and friends who have disabilities. Research information relating to issues that impact a wide range of people, such as pre-existing conditions and eligibility for health insurance, may achieve newsworthiness because the information may be relevant to those with and without self-identified disabilities. Researchers may also provide interesting information that significantly impacts the lives of a specific set of people with disabilities, such as an advanced mobility device or strategy for persons who are blind, where the reader's interest may lie in the unique or innovative nature of the research information.

Timeliness. According to Hartman and Johnson (1993) "Timeliness is one of the most important keys to newsworthiness" (p.5). However, timeliness may contrast with research

strategies such as longitudinal studies, or with the typical data analysis, preparation, and publication turnaround times of research. If a particular study, or body of research, stands out as strongly achieving the three newsworthy criteria it may be published and may create its own timeliness. In most cases, research information will be used to support disability issues or human-interest stories for which up-to-date information may be retrieved from media archives or obtained directly from the researcher.

Controversy. Current disability and rehabilitation research includes many of the controversial issues facing today's society. NIDRR-funded researchers are studying high profile issues such as drugs and disability, mental health, employment discrimination, inclusive communities, and technology for survivors of land mines. Yet when these issues reach the media, research information is seldom used to support either side of the controversy. When the media reported a Supreme Court decision providing individual in-school health services to a student with disabilities (Cedar Rapids Community School District v. Garret F., 1999), it was largely reported without research information on school inclusion. Statements from inclusion researchers could have significantly expanded the story by presenting data and testimony on the benefits of inclusion. Perhaps this lack of research information support may be explained by the media's desire to quickly report disability news and to report the case among other Supreme Court opinions handed down at that time. The media should be made aware of prevalent viewpoints and existing research concerning controversial disability issues as well as the availability of sources for reliable background and research information.



Developing Media Relations

Personal communication with journalists is essential to effective media relations. An important role of dissemination specialists, or others charged with media relations, is to represent the research organization to journalists. This linking role requires an understanding of the perspective of the organization as well as that of the journalists, with a key function of interpreting the needs, operations, and language of each. The development of media relations should be aimed at three objectives: 1) providing the media with research information for publication; 2) providing the media with research information for their archives; and 3) serving as reliable sources when research information is needed to support current stories.

Start Locally. A first step in developing media relations is to study local media outlets including television, radio and newspapers. Local media have an immediate interest in their community, like to promote community pride, and often take an interest in research conducted at a local institution. Their approach also may place research information in a local context, adding a local human face. Local journalists are also connected with national news networks. Interesting research information in local news may more easily make its way to national outlets than press releases sent directly to those outlets. In following-up a press kit the NCDDR was informed by a major newspaper that "we get over 1,000 press kits a week; if we're going to use the press kit we'll contact the source."

Research organizations have a number of options in determining who to contact in the local media. One method is to review past stories relating to people with disabilities to identify journalists who appear to be receptive to disability research information. The features editor at a newspaper often handles the health and human interest

columns where disability information is usually located. Newspapers also may have a medical editor who is receptive to disability research information and business editors may have particular interests in employment research or new product development. Researchers also may identify journalists who have a disability, a connection with a disability organization, or an interest in a disability issue. Although they may be in a different editorial department, these receptive journalists could provide a strong reference for contact with the most appropriate journalist.

Developing a Media List.

Researchers are typically knowledgeable about newsletters, magazines, and journals in their specific fields. A large number of additional media sources also may be interested in newsworthy research information. An expanded media list may include local media, media in the specific field, media sources in related fields, and disability and popular media sources.

Researchers can locate disability media sources in *America's Telability Media* (Winston, 1998) which includes over 1,200 disability media sources in a free format that can be downloaded to a personal computer <<http://www.freedomforum.org/newsstand/reports/telability/printdir.asp>>. Popular and disability media information may also be found in the *National Directory of Information Sources on Disabilities* (NIDRR, 1994); *The Complete Directory for People with Disabilities, 1998/99* (Greyhouse Publishing, 1998); and *Resources for People with Disabilities* (Oakes & Bradford, 1998).

The NCDDR has developed a media database with over 600 entries which are updated frequently. NIDRR grantees may contact the NCDDR for information about the media database.

Developing Effective Relationships.

Research organizations may help journalists to identify newsworthy topics, identify information sources, and develop interesting stories. These activities benefit journalists and researchers by increasing coverage of research information and accurate reporting. The key to developing mutual relationships is to establish and maintain credibility. Providing accurate and honest information over time earns the trust of journalists. With trust established, journalists are more likely to seek out researchers as sources of information, opinions, and linkages to additional information. In working with journalists it is vital to develop good interpersonal relationships, including following the "Five Fs of Media Relations" (adapted from Robey & Stauffer, 1995):

Fast. Researchers should respect journalists' deadlines. Return phone calls immediately, even if it is past normal office hours. Return email messages within the day they are received, if possible.

Factual. Provide factual information with an interesting human face. Provide research information in a highly readable format. Journalists may also appreciate creative or dramatic statements and personal or human-interest anecdotes to help illustrate the research information. Give sources for additional facts and statistics.

Frank. Be open to the journalists' questions and respond with honest answers. Journalists will respect an honest inability to answer a question.

Fair. Researchers should be fair to journalists if they expect fairness from them. Provide equal amounts of information to all journalists.

Friendly. Remember journalists' names and review examples of their past writing. Develop a cooperative relationship by listening to their perspectives, knowing their interests, and extending your appreciation when they cover the research information.

Submitting Research Information: Developing Press Kits

The press kit is a standard way to provide information to the press (Robey & Stauffer, 1995). A press kit is a packet of materials that helps journalists understand the organization and its research, and helps them to develop their stories. Press kits are useful in introducing researchers to journalists, providing technical information about the research, promoting the information for press coverage (with human-interest information), and in providing information about larger issues involved in the research. Press kits may include the following components:

- Cover memo or letter;
- Press release;
- Fact sheet(s) on newsworthy issues or events;
- Supportive comments from fellow researchers, disability associations, persons with disabilities, etc.
- Press clippings from previous coverage of the organization or its research;

- Reprints of relevant supporting information;
- Photographs of research participants;
- Necessary charts and graphs;
- Background information about the organization and/or funding source;
- Background information about the area of research;
- Biographical sketches of key researchers; and
- Business card of principal investigator or contact person.

(Adapted from Robey & Stauffer, 1995)

The Press Release. The press release is the mainstay of media relations and is the most accepted, cost-effective way to reach journalists. A press release includes information prepared for the media as a "ready-to-run" story. If a press release contains newsworthy information and is well-written it may be printed virtually unchanged. Press release contents may also refer journalists to additional information in the press kit to help them enlarge the story. Press releases should include summative and interesting information about the research in an effort to catch the interest of the journalist.

Today, electronic mail has become a preferred method of communication. It may be advantageous to use a combined approach, with an emailed press release followed by a hard-copy version of the research information and supporting documents in a press kit. Emails allow journalists to start a story immediately and use the more comprehensive press kit to expand and complete the story.

Conclusion

Including research information in the popular and disability media provides researchers with concerns and ideas for extending their dissemination activities to the information sources that are most frequently accessed by people with disabilities and the general public. The future holds a great promise for expansion of customer-driven services in integrated community settings. This requires that communications between researchers, people with disabilities, and communities take place in the forums operated and accessed by the targeted users of research information.



Sharing Research Information with the Disability Media

Following the distribution of a press release and press kit, in early 1999 the NCDDR contacted several publications that commonly feature a variety of disability issues and lifestyles. The purpose was to 1) learn how they would prefer disability research information be submitted to them, and 2) what kinds of research information would be most relevant for their publication.

Seven publications were contacted by electronic mail, including: *Ability*, *DAV (Disabled American Veterans)*, *En•a•ble* (no longer published), *New Mobility*, *Quest*, *Ragged Edge*, and *WE* magazines.

In responding to the first item, four of the magazines indicated that they prefer that researchers submit a press release. Similarly, four of the magazines indicated that press releases should be submitted using email. Only one (*Ability*) indicated a preference for

a pre-written story. None of these magazines want researchers to contact their staff directly.

The second item asked respondents to identify the most relevant types of disability research information, including:

- a. ADA or policy research,
- b. Employment strategies,
- c. Disability statistics,
- d. Independent living research,
- e. Adaptive equipment research,
- f. Universal design research,
- g. Mental health research,
- h. Mental retardation research,
- i. Medical rehabilitation research, and
- j. All areas

Six of the magazines indicated "All areas." One identified ADA or policy research, employment strategies, disability statistics, adaptive equipment research, and universal design research as most relevant.

All but three respondents indicated priorities among the information categories. The research areas with the highest priorities were ADA or policy, universal design, adaptive equipment, and employment strategies. Lowest priorities identified were mental retardation, mental health, and independent living research. (*Questionnaire data available from the NCDDR upon request.*)

These responses from disability media representatives indicate a receptiveness to disability research information on a variety of topics. For the most part, researchers should feel comfortable in developing content directed at a specific publication. The target publication should be thoroughly reviewed and the researcher should determine whether their research information is immediately relevant to the publication's audience and potentially interesting to its readers.

Anatomy of a Press Release

(Headings from Press Flash, 1999)

1. A standard introduction
for a press release:
FOR IMMEDIATE RELEASE

FOR IMMEDIATE RELEASE

Rick Blount
University of Vermont
Office of Public Relations
86 South Williams Street
Burlington, VT 05401-3404
802-656-2005
rblount@zoo.uvm.edu

2. Who to contact for more
information.
This may be the sender of the
press release, such as a university
public relations department.
Typically name, address, and
phone are included.

3. Succinct title that entices
the reader.

"VIRTUAL CORSET" FOR BACK PAIN BEING
FIELD-TESTED IN VERMONT

The headline should attract
attention to the release by
highlighting a newsworthy
aspect of the research.

BURLINGTON, VT, Sept. 29, 1997. Whenever Stowe Landscaper Christopher Janes bends his torso to pull a weed or lift the wheel of his lawnmower, the change in inclination is recorded by an electronic device strapped to his chest. If Janes bends far enough to risk straining his back, the device—which is housed in a plastic case used for electronic pagers—vibrates to warn him about the danger.

4. Begin with the location
and date, followed by
an introduction covering
all major points.

The introduction should
provide a concise overview
of the press release. "Don't give
all the details." Construct the
introduction so that if someone
read it they would have a good
idea about the rest of the press
release (Hartunian, 1999).

The electronic device—dubbed the "virtual corset"—is being tested by University of Vermont (UVM) researchers as a potential improvement on the cloth corsets or harnesses some workers use to avoid straining their backs. Field testing of the virtual corset follows six years' work on such devices by researchers at UVM's Vermont Back Research Center, the nation's only federally funded lowback pain rehabilitation research and information center. The latest model was developed in cooperation with Microstrain, Inc., a Burlington-based company started by UVM researchers and former students.

Janes is the 26th participant in the new study, which involves four weekly visits by researchers to participants' worksites around the state. The owner of Eastern Exposure Landscaping in Stowe, and the newly opened Summer Breeze fitness center in nearby Morrisville, Janes hurt his back in May while lifting heavy equipment onto a trailer. But after a couple of weeks in the study—including one with the device's vibration function turned off, Janes reported that it seemed to have reminded him to avoid bending in ways that risk reinjury.

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This press release from the NIDRR-funded Vermont Back Research Center was originally submitted to the *Burlington Free Press*. It was picked up on the news wire and led to subsequent articles in:

The Detroit News, January 20, 1998 <<http://www.detroitnews.com/1998/discover/9801/20/index.htm>>

MSNBC, August 24, 1998 <<http://www.msnbc.com/news/190131.asp>>

Smithsonian Magazine, August 1998 <<http://www.smithsonianmag.com/smithsonian/issuesall/issues98/aug98/back.html>>

"With the thing turned off I kind of miss it," he said. "I'll bend over and think 'it ought to be going off now.'"

By following Janes and others to their actual worksites, UVM researchers James Fox and Lise MacDonald hope to get real-world feedback on the effectiveness of their device and on the correlation between bending and back pain. In the current study, data from the devices will be correlated with participants' reports of pain, as well as their range of motion and other measures of back function.

Freed from the laboratory by portable data-collection devices and laptop computers, the researchers also hope to make participation in their ongoing studies more convenient for Vermonters—yielding more participants and fewer dropouts.

"The easier we make it for participants, the longer they'll stay in the study," said MacDonald, Vermont Back Research Center's human research coordinator. "It makes sense to go out of our way to study participants. After all, they're doing us a tremendous service."

The device also offers a unique way to take the back pain research out of the laboratory and into the fields, factories, quarries, and other worksites where so many people injure their backs. Low back pain is the most common musculoskeletal disorder, a leading cause of doctor visits, and the most frequent source of disability-related claims filed with the Equal Employment Opportunity Commission. Back pain affects 80 percent of Americans at some time in their lives and costs the nation an estimated \$50 billion to \$100 billion each year in medical treatment, worker compensation, and lost productivity.

Funded by the National Institute on Disability and Rehabilitation Research, the Vermont Back Research Center also provides information services such as bibliographic searches and fact finding, as well as consulting services in the areas of rehabilitation engineering and ergonomics.

For further information about the Back Research Center contact:
University of Vermont
Vermont Back Research Center
One South Prospect Street
Burlington, VT 05405
1-800-527-7320
<<http://salus.med.uvm.edu/~backtalk/>>

5. A quote by a company representative adds credibility to your release.

A quote from the lead researcher, plus their credentials, adds credibility to the research process. A quote from person(s) with disabilities adds a "human face" to the press release and credibility to the impact of the research.

6. Include information about why this event is newsworthy.

Include information about important facets of the research and how the research will improve the lives of people with disabilities. This section should add interesting details to the release without overwhelming the reader. Readers may get additional details from the background information in the press kit.

7. Conclude with further contact information.

This may include the originator of the information, such as the researcher's name, address, phone, email, and Web site URL. Toll-free telephone numbers and email addresses are particularly useful for contacts from journalists.

Contact Information for Selected Disability Media

The NCDDR identified the following radio show and magazines as having either a broad-based readership or representing a significant disability area. This is not an exclusive or exhaustive list and readers should consult *America's Telability Media* (Winston, 1998) or contact the NCDDR for information about additional disability media.

Ability magazine

1001 W. 17th St.
Costa Mesa, CA 92627
Phone: 1-714-854-8700
Email: ability@pacbell.net
URL: <http://www.abilitymagazine.com/>
Publisher and Editor: Mr. Chet Cooper

The Arc Today

The Arc
500 E. Border St., Ste. 300
Arlington, TX 76010
Phone: 1-817-261-6003
Email: thearc@metronet.com
URL: <http://TheArc.org/>
Editor: Mr. Jim Humphrey

DAV Magazine

DAV Editorial Office
P.O. Box 14301
Cincinnati, OH 45250-0301
Phone: 1-606-441-7300, or
1-202-554-3501
Email: ahdav@one.net
URL: <http://www.dav.org>
Publisher: Mr. Arthur H. Wilson
Editor: Mr. Arvel "Jim" Hall

New Mobility magazine

P.O. Box 220
Horsham, PA
Phone (Publisher): 1-888-850-0344
Email (Publisher): Ginal@jvleonard.com
URL: <http://www.newmobility.com/magazine/>
Publisher: Leonard and Associates
Editor: Barry Corbet (Golden, CO)

On a Roll!

1117 Livermore Street
Yellow Springs, OH 45387
Phone: 937-767-1838
Call-in Line: 1-800-289-8255
Email: greg@onalrollradio.com
URL: <http://www.onalrollradio.com/>
Syndicated by: Radio Center for People with Disabilities
Host: Greg Smith

Paraplegia News

Paralyzed Veterans of America
2111 E. Highland Ave., Ste. 180
Phoenix, AZ 85016
Phone: 1-602-224-0500
Toll Free: 1-888-888-2201
URL: <http://www.pva.org/pn/>
Contact: Mr. Cliff Crase

QUEST magazine

Muscular Dystrophy Association
3300 East Sunrise Drive
Tucson, AZ 85718-3208
Phone: 1-800-572-1717
Email: mda@mdausa.org
URL: <http://www.mdausa.org/publications/Quest/quest.html>
Editor: Mr. Bob Mackle

Ragged Edge

P.O. Box 145
Louisville, KY 40201
Phone: 502-894-9492
Email: editor@ragged-edge-mag.com
URL: <http://www.ragged-edge-mag.com/index.shtml#edge>
Publisher: The Advocado Press
Editor: Mary Johnson

Supported Employment InfoLines

Training Resource Network, Inc.
P.O. Box 439
St. Augustine, FL 32085-0439
Phone: 1-904-823-9800
Email: trninc@aol.com
URL: <http://www.trninc.com/>
Editor: Mr. Dale DiLeo

WE magazine

495 Broadway, 6th Floor
New York, NY 10012
Phone: 1-212-941-9584
Email: charles@wemagazine.com
URL: <http://www.wemagazine.com/>
Publisher: Dr. Cary Fields
Editor: Dr. Charles A. Riley

Publishing in Journals

Publishing research results in refereed scholarly journals has long been a hallmark of success for researchers. These contributions to the literature have served as traditional avenues for researchers to share their results with colleagues. In the near future, NIDRR's indicators for the Government Performance and Results Act (GPRA) will attach special significance to publishing articles in refereed journals as a demonstration of NIDRR's overall performance (B. J. Berland, personal communication, May 6, 1999).

Publishing articles in refereed journals achieves the following goals:

- *Fosters scientific rigor.* Publication in refereed journals adds status to the research information, and to the source of the information, since the inclusion of an article is the result of scrutiny by experts in the field who signify that the research information is significant and the data have passed their critical evaluation.
- *Validates research strategies.* Acceptance by experts indicates that the research information is original, useful, and provides valuable new knowledge.
- *Facilitates replication of research studies and generalizability of results.* Journal articles generally provide in-depth and complex information that may serve as a basis upon which other researchers may conduct similar research or directly apply the research information to real world situations.
- *Improves accountability.* Publishing in refereed journals has been the classical means by which academicians account for their research activities to their institutions. Journal publishing can provide accountability to stakeholders who review the researcher's publications to determine whether they are a credible source of information.

Submitting a manuscript to a scholarly journal does not mean it will be published, as many journals have very high rejection rates. The American Psychological Association (APA) publishes 25 journals and 2 special journals. The average rejection rate for APA journals was 73 percent in 1997. This ranged from 3 smaller journals with rejection rates of 31-54 percent and circulation of less than 2,000, to 17 larger journals with rejection rates of 72-96 percent and circulation from over 3,000 to over 10,000. *American Psychologist*, a special journal with over 110,000 subscribers, rejected 78 percent of the manuscripts submitted in 1997 (APA, 1998).

Several NIDRR grantees have asked the NCDDR to share information helpful to increasing the acceptance of articles for publication. NCDDR staff contacted editors of journals that have published articles by grantees and staff members of grantees with a successful publishing record. In these discussions, editors and authors were asked for suggestions that could be shared with NIDRR grantees to enhance successful writing for journal publication.

Tips for Journal Article Submissions

In selecting articles for publication, editors consider the importance of the subject, scientific merit, research methodology, quality of writing, interest to their readership and its fit with the journal's mission. Successful articles in refereed journals are viewed by editors as having original, well-conceived hypotheses, and maintaining high levels of internal, ecological, and external validity. Two editors, Dr. Barbara Uzell of *Applied Neuropsychology* and Mr. Bradley Johns of the *American Journal of Physical Medicine and Rehabilitation*, agree that the author of a publishable article must:

- *Use sound research methods and contribute something new to the field.* Editors initially look for a sound scientific method that fits with the review of literature. If nothing new is found, it may be difficult to find a journal with interest in publishing the article.
- *Choose a journal that is consistent with the type of information and research topic of the article.* Authors

should review journals that relate to their research topics and match their submission to journals that include similar content. In some fields, particular journals may include more theoretical articles or position papers, whereas other journals may present basic or applied research articles.

- *Prepare the article according to the journal's preferred style.* Submission guidelines are available upon request from the journal's publisher and many journals provide them in each year's first edition. Also, many journals post their guidelines on their Web sites. Authors need to acquire, review, and follow these guidelines when developing their submissions. If, for example, the references are prepared in the wrong style, the editor will know immediately that the author failed to look carefully at the journal's requirements.
- *Write and rewrite the article as many times as necessary to achieve a clear and flowing text.* Authors

continued

The Peer Review Process

1. The manuscript is accepted for review.

The author(s) have followed the journal's guidelines in development and submission of the manuscript.

2. Manuscript read by editors.

Editors review manuscript and send it to reviewers. In some cases editors reject manuscripts due to poor writing, poor study design, or obvious bias.

3. Blind peer review.

Editors choose two or more reviewers to evaluate the manuscript. Typically reviewers are selected from the journal's "Board of Editors" for expertise specific to the article's topic. Reviewers receive manuscripts that do not have author

or institution information included. They review each manuscript, provide comments in their reports to the editor, and pass judgment on the article, commonly "publish," "publish with revisions," "re-submit with revisions" or "do not publish."

4. Editorial decision. The editors consider the comments and judgments of peer reviewers and make a decision based on the reviewers' reports and their own reviews of the manuscript.

5. Revision and resubmission.

Author(s) revise or rewrite the article and submit it for review by one or more of the original editors and/or reviewers. Suggested revisions are checked and approved.

6. Production. The author(s) provide the final copy of the manuscript according to the editor's specifications. New possibilities for electronic submissions may change the nature of production. At this time copyright releases are usually signed by the author(s) allowing the publisher to hold the copyright. The publisher also sends galley proofs to the author(s) for final corrections or changes prior to printing.

7. Final publication. Article appears in the journal, author(s) are provided with reprints of the article (typically 50-100) for distribution upon request. (Day, 1994)

Publishing in Journals

continued

may circulate drafts to colleagues for an internal review to assist in developing clarity of the concepts, as well as figures and graphs. The assistance of an editor or someone with an English or grammar background can be useful to ensure the quality of the writing.

- *Include a concise abstract that gives the reader an accurate picture of the article's content.* Many editors consider the abstract the most important part of an article, since some readers will read only the abstract, while others will read the abstract to see if they want to read the article.

A well-written abstract should:

1. state the principal objectives and scope of the investigation,
2. describe the methods employed,
3. summarize the results, and
4. state the principal conclusions (Day, 1994, p. 30).

In writing an abstract, every word should be carefully thought out and every sentence should clearly describe an important aspect of the research (B. Uzell, personal communication, June 23, 1998; B. Johns, personal communication, June 26, 1998).

Tips from a Successful Grantee

The Missouri Arthritis Rehabilitation Research and Training Center (MARRTC) has a successful track record of publishing articles in a variety of journals. Dr. Jerry C. Parker, Co-Director and Director of Research, discussed a number of key elements in MARRTC's research and publication process.

- *Maintain core staff.* Perhaps the most important foundation for success in research and publishing is working with research assistants and other key people so that they stay with projects over time and build long-term expertise in database and research systems. Paying attention to the positive effects of longevity pays dividends in the quality of

research performance. This requires strong institutional support.

- *Emphasize project design at the beginning.* Researchers should invest time and energy in designing well-conceptualized projects with a minimum of "front-end-flaws," keeping in mind potential reviewer concerns before beginning a research project. MARRTC has designed a number of studies that yield both primary data for an initial article and secondary data for subsequent articles.
- *Create a research culture and close working relationships.* Developing research teams for each project, with cooperative activities assigned to each team member, helps establish a strong research culture. Providing collaborative and accessible resources will help each team complete tasks on time. Teams with minimal vertical hierarchy will encourage maximum cooperation. Scheduling meetings to monitor the status of projects allows each team to make necessary changes, keep abreast of each person's work, and provide a forum for critiques and suggestions. Utilize the insight and intuition of research participants by including them as team members.
- *Monitor projects closely and set expectations for productivity.* Research teams should develop project timelines with key objectives to be attained by defined, but flexible, dates. The Research Director may monitor each project according to its timeline and assist in developing strategies to alleviate slippage.
- *Keep the paper moving.* Identifying specific staff members with time allotted to facilitate the process of developing manuscripts is important to keep a paper moving. For example, MARRTC has a typist whose first priority is preparing and revising manuscripts. If staff members have to try to "work in" time for articles, things may slow down and the process may become more cumbersome.
- *Edit the paper rigorously.* Since clarity of the paper is of utmost importance, researchers and other

staff need to work together to effectively edit the paper. Development of an editing sequence and structure facilitates the editing process, so that authors know exactly who and what processes the paper must go through. An editing structure eliminates duplication and confusion in bringing the paper to a final form. It is also beneficial to have a person with extensive publishing experience review the paper for sentence structure, wording, and grammar.

- *Target a journal carefully.* Choosing a journal that is consistent with the topic and preparing the article according to the journal's style cannot be overemphasized. Authors increase the chances that their articles will be selected for publication in a specific journal when they ensure that the article meets specific selection criteria.
- *Make responsive revisions.* When an article is returned for revisions or in some cases, rewriting, the author should look constructively at the reviews and attend to the reviewers' comments by making changes to meet their concerns (J. C. Parker, personal communication, June 26, 1998).

New Roles and Opportunities

Choosing an appropriate journal and carefully following the author guidelines are critical to a successful submission. Several grantees employ a dissemination specialist to oversee the development of all publications, and to help focus staff efforts. A dissemination specialist may work closely with both researchers and clerical staff to develop final drafts for submission.

Current publishing activities maintain a tradition of rigorous peer review and concern for quality. New challenges to this tradition are emerging with electronic and online publishing. These challenges provide opportunities to improve and, in some cases, streamline the peer review process as well as increase the availability of research information through both print and online journals.



Publishing on the Internet: Possibilities and Problems

The role and influence of refereed journal publications are changing due to the emergence of the Internet and the World Wide Web. Research information can be posted on Web sites for immediate review, printing, or downloading. With these innovations come controversies over Internet publishing of non-refereed research, how the peer review process may differ, and how quality may be maintained given the increasing volume of research information provided on the Internet.

Such prestigious publications as the *New England Journal of Medicine*, *The Lancet*, the *British Medical Journal*, the *Journal of the American Medical Association*, and the *Medical Journal of Australia* have all presented concerns about Web publishing (Wouters, 1999). Posting research information on the World Wide Web provides opportunities to quickly display new medical treatments or concerns before they appear in print editions. Such rapid posting includes a quick turnaround time for submission, review, revision, and online publication. Rapid submission and review strategies typically speed up traditional means of manuscript submission and review through mail, express mail, or faxes. However, new strategies are being developed including restricted Internet submission of manuscripts and review via online forms, and the use of electronic mail in the review process.

The main purpose of quick posting by these well-known sources is a reduction in reliance on nonrefereed, and potentially dangerous, medical information that is increasingly appearing on the Internet. By providing fast review and publication these journals serve as sources for urgently needed medical information. A faster turnaround time from medical research to publication has a significant value in speeding medical

interventions to physicians, and to patients, with the caveat that safety requires a thorough review.

Two Examples

The *New England Journal of Medicine* and the *Journal of the American Medical Association* have developed strategies for speeding the turnaround time for publication of urgent medical research articles. The editorial policy of the *New England Journal of Medicine* states that "For studies submitted to us that have immediate health implications, we will continue our efforts to see that dissemination of urgent medical information is not delayed by either peer review or the publication process" (Kassirer & Angell, 1995, p. 1710). This policy means that certain urgent articles will receive immediate attention by reviewers and will be published in the online edition weeks before appearing in the print edition. According to Jerry Kassirer, M.D., the journal's editor,

Only very specific papers that have urgent medical implications are rushed through the peer review process and can then be published on the Internet weeks before they otherwise would have been. Our peer review process normally takes not more than two weeks, our accelerated procedure is a matter of days. In short, the Internet is very useful to get information out quickly, but its content must be guarded very carefully. If not, it will promote medical rumors instead of diffusing dispassionate scholarship. (Kassirer, 1998)

The *Journal of the American Medical Association* takes a similar approach with "JAMA-EXPRESS: Rapid

Peer Review and Publication."

JAMA-EXPRESS follows their editorial contention that "With the speed of communication afforded by the Internet both before and after publication, the option of rapid review and publication is not just possible but essential for a biomedical journal" (Winker & Fontanarosa, 1999). JAMA has targeted a turnaround time of four weeks from submission to posting on the JAMA Web site for extremely important articles, and six weeks from submission to print publication of EXPRESS articles. Initially, editors screen articles before formal submission and contact peer reviewers about incoming articles. Using the same rigorous peer review and editorial evaluation as for other articles, EXPRESS articles are reviewed within 48 hours, with editorial review and request for revision completed in 72 hours. Authors then make their revisions within 48 hours and return final proofs within 24 hours. Finally, editors, copy editors, and production staff complete the same quality steps as for JAMA, but much more rapidly.

Characteristics of Online Journals

NCDDR staff searched the World Wide Web to learn about journals' online presence. The *Compendium of Products by NIDRR Grantees and Contractors-FY 1996* (NIDRR, 1997) was reviewed to identify journals that published articles from NIDRR grantees. A database of 264 journals was developed, and of these, 238 were found to have some type of online presence. This may be an individual Web site, or as a part of an associations' or publishers' Web site. Some general variations appear across the presentations of these journals on the Internet.

continued

- The purpose of Internet presentation may be to provide simple information about the journal, to promote sales of the journal, to offer online abstracts, and in some cases, full text of journal articles. Journals representing associations may simply be listed or briefly described on the associations' Web site, particularly those that are purchased only through membership. A publisher's Web site may include an "online store" using shopping carts, checkouts, and other merchandising strategies.
- Online editions may provide full text articles only to subscribers. Many online editions provide nonsubscribers with abstracts of all articles, archived for the past several years, and may provide feature articles within current and archived issues.
- Web sites that offer online editions are more likely to be stand-alone journal sites, such as the *New England Journal of Medicine*, or associations which feature the journal as a major activity, such as the *Journal of the American Medical Association*.
- Publishers typically present an information page and author guidelines page for each journal. Some journal subscriptions include print only, online only, or print and online editions (at a higher cost).
- Medical or biomedical journals are more likely to have online editions than journals concerned with education or social services.
- Foreign journals, primarily British and European, are more likely to have online editions available to subscribers. This may be due to printing and postage costs, and the time necessary for print mailings.

Online Submission to Journals

Several journals now have some form of rapid online submission, review, and publication process. The online journal *Brain Research Interactive (BRI)* uses a program called "Smart Works" <<http://smart.scripps.edu:8000/smart.htm>>

that provides authors the option of using the "Smart Submitter," which provides a set of online forms for submitting a manuscript. The work is reviewed by peers who have been invited to review articles using the online "Smart Reviewer." The "Manuscript Review" feature allows an author to enter a code number to access the reviewers' comments. Following the online review, the author can quickly make revisions and submit the revised manuscript online, allowing journal staff to quickly publish the article both online and in the next available print edition. According to *Smart Works* (1997) "Advantages are greatly reduced time-to-review, time-to-publish, and time-to-read periods."

The *Journal of Neuroscience* has a large section in the online edition devoted to Rapid Communications articles, providing authors with the option of quickly publishing their articles on the Web site only. In the opinion of G.M. Shepherd, the Journal's editor,

The first advantage will be a significant reduction in the delay between the time that a manuscript is approved by the editors to the time that it is published in the online Journal. The aim is to reduce that time to less than one month while still maintaining the high standards of copy editing and data presentation that are associated with the Journal. This represents a considerable improvement over the time in press for the hard copy version, two to three months, as in other journals (Shepherd, 1999).

Information Technology and Disabilities (ITD) is an online journal to which authors submit their manuscripts electronically in a PC format, via disk or email. ITD is the journal of Equal Access to Software and Information (EASI) and must remain accessible to all persons who review ITD on their Web site <<http://www.rit.edu:80/~easi/itd.html>> (EASI, 1996).

Guidelines for submissions. In the NCDDR review of online journals, 164 were found to provide author guidelines on their Web sites. In specifying a standard manuscript or reference style, 83 journals require American Psychological Association style (APA, 1995); 21 journals require Uniform Requirements for Biomedical Journals (ICMJE, 1997); 9 journals require the Council of Biology Editors Style Manual (CBE, 1995); and 9 journals require American Medical Association style (AMA, 1997). The 42 remaining journals require other styles or have developed their own unique requirements.

It is extremely important to obtain the publisher's author guidelines and have a knowledge of their preferred style before developing a manuscript. The guidelines may specify a standard style yet provide additional requirements which may modify or contradict aspects of the standard style. Many of the journals' online author guidelines do not specify a standard style but provide extensive individual style instructions and examples. This practice is particularly prevalent in British and European journals. Authors should review the online guidelines, if available, and it is advisable to contact the publisher or editor for the most up-to-date version of the guidelines before proceeding.

Exclusive publishing concerns and copyright.

In addition to speeding information transfer, the Internet also provides a medium for authors to directly publish their work. The APA (1999) has identified three major problems with publishing on the Internet:

- Notices in some journals (such as *Neuroscience* and the *New England Journal of Medicine*) alert authors that papers posted on the Internet are considered already "published" and will not be considered for print publication.
- Papers posted on the Internet may be considered in the "public domain" and downloaded, incorporated into someone else's work and copyrighted by them (i.e., authors can "lose" their own copyrights and their own right to print publication).

- Posting a published paper on the Internet may violate the copyright transfer agreement related to the print publication (APA, 1999).

The APA has a revised "interim policy" that allows prior Internet publication of an article, provided it is labeled as a draft that has not been peer reviewed. Upon acceptance for publication the article's copyright is transferred to the APA and the full text of the article must be removed from the author's or other Web sites. The APA further states that "Many of the legal issues surrounding the Internet, online services, service providers, and copyright and privacy in the electronic world are murky, confused, in the courts or soon to be there, and, of course, rapidly changing" (APA, 1999).

Online and print journals approach these issues in a variety of ways, from an outright ban on publication of an article's information in any form through any medium, to allowing publication of abstracts or less complete descriptions of the information presented in an article, to freely allowing prior and re-publication of complete articles.

Some journals allow authors to retain the copyright for their articles. However, in most cases, the journal either assumes the copyright under their name through an explicit statement in their author's guidelines or requires that the author transfer the copyright in writing (see Copyright Statement Sample). Several journals have online copyright transfer forms that can be printed from the journal's Web site or downloaded.

It is imperative that authors carefully review a target journal's author guidelines paying particular attention to exclusive publishing stipulations and copyright requirements. The exclusive copyright requires that the article has not been, nor will be, published in other journals or print and online media. This means that authors are not allowed to republish the article on the Internet or in books and other journals.

Citing Internet Sources.

Many journals have specifications for citing and referencing Internet sources. Authors should also be

aware that instructions for citing and referencing Internet sources are available on the American Psychological Association (APA) Web site at <http://www.apa.org/journals/webref.html>. Information about citing and referencing for manuscripts to biomedical journals and others may be found on the Himmelfarb Health Sciences Library Web site at <http://www.gwumc.edu/Library/cite-int.htm>.

Conclusion

With the increasing speed of information transfer, the role of refereed journal publications will continue to change. Research information is often posted on Web sites for immediate review, printing or downloading. Research activities are more customer-driven with an explicit need for the research information to be

immediately relevant to and understood by people with disabilities. With these innovations a divergence of publishing activities may occur where researchers in medical fields will continue to rely on print and online publication in refereed journals to validate their research results.

Researchers in direct service or advocacy fields are also discovering the Internet as a medium for publishing their research information directly, without peer review, and in refereed journals. Current and future developments will continue to expand the use of the Internet and both refereed and nonrefereed research information will reach wider Internet audiences.



Copyright Statement

SAMPLE

Copyright agreement and submission letter:

The following agreement, signed by the corresponding author, must accompany each submitted manuscript:

The undersigned author transfers all copyright ownership of the manuscript entitled (title of article) to the American Society for Surgery of the Hand in the event the work is published. **The undersigned author warrants that the article is original, is not under consideration by another journal, and has not been previously published. I sign for and accept responsibility for releasing this material on behalf of any and all coauthors.**

When submitting a paper the author(s) must make a full statement to the editor about all submissions and previous reports that might be regarded as prior or duplicate publication of the same or very similar work. Copies of such material should be included with the submitted paper to help the editor decide how to deal with the matter.

From the *Journal of Hand Surgery* (1999)
<http://www.churchillmed.com/Journals/USHand/authors.html>

(Used with permission of Harcourt Publishing.)

Selected Journals with Online Editions

From the NCDDR's database of journals that have published articles from NIDRR grantees

American Journal of Audiology

<<http://journals.asha.org/aja/>>

American Journal of Clinical Pathology

<<http://www.ascp.org/press/periodicals/eajcp/jun99/index.html>>

American Journal of Respiratory and Critical Care Medicine

<<http://ajrccm.atsjournals.org/>>

American Journal of Roentgenology

<<http://www.arrs.org/ajr/>>

Archives of Neurology

<<http://www.ama-assn.org/public/journals/neur/neurhome.htm>>

Archives of Physical Medicine and Rehabilitation

<<http://www.archives-pmr.org/>>

Brain Research

<<http://www1.elsevier.nl/journals/bres/>>

The British Journal of Social Work

<<http://www3.oup.co.uk/jnls/list/social/>>

Community Mental Health Journal

<<http://www.catchword.co.uk/titles/00103853.htm>>

Disability and Society

<<http://www.carfax.co.uk/dso-ad.htm>>

Dysphasia

<<http://link.springer.de/link/service/journals/00455/index.htm>>

The Georgetown Public Policy Review

<<http://www.georgetown.edu/publications/GPPR/>>

Information Technology and Disabilities

<<http://www.rit.edu/~easi/itd.html>>

Journal of the Acoustical Society of America

<<http://ojsps.aip.org/jasa/>>

Journal of the American Academy of Orthopaedic Surgeons

<<http://www.jaaos.org/>>

Journal of the American Medical Association

<<http://www.ama-assn.org/public/journals/jama/jamahome.htm>>

Journal of Applied Behavior Analysis

<<http://www.envmed.rochester.edu/wwwrap/behavior/jaba/jabahome.htm>>

Journal of Clinical Psychology

<<http://www.interscience.wiley.com/jpages/0021-9762/>>

Journal of Immunology

<<http://www.jimmunol.org/>>

Journal of NeuroOncology

<<http://www.wkap.nl/journalhome.htm.0167-594X>>

Journal of Neurophysiology

<<http://jn.physiology.org/>>

Journal of Neuroscience

<<http://www.jneurosci.org/>>

Journal of Pediatric Psychology

<<http://www.oup.co.uk/jpepsy/>>

Journal of Prosthetics and Orthotics

<<http://www.oandp.com/organiza/aaop/educ/pub/jpo/index.htm>>

Neurosurgery

<<http://www.neurosurgery-online.com/home.html>>

New England Journal of Medicine

<<http://www.nejm.org/content/index.asp>>

Pediatrics

<<http://www.pediatrics.org/>>

Pediatrics in Review

<<http://www.pedsinreview.org/>>

Physical Therapy Journal

<http://www.apta.org/pt_journal/>

Physics in Medicine and Biology

<<http://www.iop.org/journals/pb/>>

Radiology

<<http://www.rsna.org/REG/publications/rad/rad.html>>

Respiratory Care

<<http://www.rcjournal.com/>>

SIGCHI Bulletin

<<http://www.acm.org/sigchi/bulletin/>>

Social Behavior and Personality

<<http://www.psycholjournal.co.nz/>>

Society of Automotive Engineers Technical Paper Series

<http://www.sae.org/products/papers/papinfo/pap_idx.htm>

Spine

<<http://journals.lpub.com/spine/>>



NCDDR's Journal Database

The information collected from NCDDR's review of 264 journals that have published articles by NIDRR grantees has been entered into a database. Information was also gathered from publishers who were contacted by telephone. These data include title; publisher; contact information; editorial description; target audience; ISSN number; Web availability; Web address; description of online presence; availability of author guidelines; style requirements; subscription information; frequency of publication; circulation; and indexing. All information was not found for all journals. NCDDR staff are considering making this database available online, to assist authors in identifying and contacting appropriate journals.

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NIDRR Grantees Receive Recognition

The NCDDR congratulates each of the following NIDRR grantees and staff members. All grantees are encouraged to contact the NCDDR with information to share in future issues of *The Research Exchange*.

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Mary Hibbard, Ph.D., Director of Research at the **RTC on Community Integration of Individuals with Traumatic Brain Injury**, Mt. Sinai Medical Center, was awarded the *Congressman Ted Weiss Consumer Advocacy Award* by the Brain Injury Association of New York State at their annual meeting in June, 1999. **Dr. Hibbard** received the award for overall excellence in TBI rehabilitation. The award commemorates the late Congressman Ted Weiss who exposed corruption in the TBI rehabilitation industry during the 1980s and early 1990s. For more information contact **Dr. Wayne Gordon**, Director of the **RTC**, at (212) 659-9372.

~

Staff members of the **Research and Training Center on Rural Rehabilitation Services (RTC: Rural)** at the University of Montana have been recognized with special awards and honors:

- **Dr. Tom Seekins**, Director, has been elected President of the American Association on Health and Disability for 1999-2000. This organization is dedicated to the support, study and encouragement of efforts to prevent primary and secondary disabling conditions, and to promote the health of people with disabilities.
- **LaDonna Fowler**, Director of the **American Indian Choices: Culture and Context Project** has been appointed Chairperson of the Subcommittee on Disability Issues of the National Congress of American Indians (1999-2000).
- **Alexandra Enders, OTR**, Research Associate, has been elected President of RESNA, the international organization of professionals in the field of assistive technology for 1999-2001.
- **Nancy Arnold, Ph.D.**, Research Director, has been elected President of the Montana Association for Rehabilitation for 1999-2000.

For further information contact **Diana Spas**, Information Specialist at the **RTC on Rural Rehabilitation Services**, at (888) 268-2743.

How To Contact The National Center For The Dissemination Of Disability Research



Call Us

1-800-266-1832 or 512-476-6861 V/TT
8 A.M.-NOON and 1 P.M.-5 P.M. C.T. Mon.-Fri.
(except holidays) or record
a message 24 hr./day



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Exchange

VOLUME 4, NUMBER 4

1999

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A WORD FROM THE DIRECTOR

NCDDR Completes Pilot Phase

NIDRR's notice of final funding priorities issued in the *Federal Register* of November 18, 1994 called for applications to establish a Center for the Dissemination of Disability Research. The announcement indicated:

Researchers usually report research findings through professional meetings and publications. In order to expand dissemination of research findings to other audiences, including rehabilitation professionals, individuals with disabilities, and other interested parties, researchers may need technical assistance and training. Research is needed to understand the reasons why persons are not utilizing information from NIDRR-sponsored research. (p. 59834)

The establishment of the **National Center for the Dissemination of Disability Research** (NCDDR) at the Southwest Educational Development Laboratory has provided a unique opportunity for staff to learn and demonstrate new strategies/approaches as a part of NIDRR's pilot project. While the conference and publication practices of NIDRR researchers

have not been radically changed, they have been influenced to include additional dissemination strategies to expand the availability, outreach, and utilization of disability research outcomes and expertise.

The NCDDR has worked to facilitate measurable increases in the production of a variety of new formats and strategies to make new audiences aware of NIDRR grantees' significant information and service resources. NCDDR staff have worked

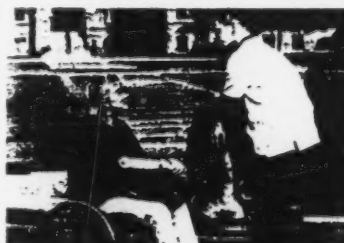
At a Glance

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How Do NIDRR Grantees Disseminate Information?

Are the results of disability research useful to people with disabilities? If so, where and how do people find such information? How do service providers and others generally get information to consumers? Would the information be more useful if it were more accessible? The National Center for the Dissemination of Disability Research (NCDDR) conducted a three-phase nationwide survey to find answers to these and other related questions.

Each phase focused on the sampling of one major group:



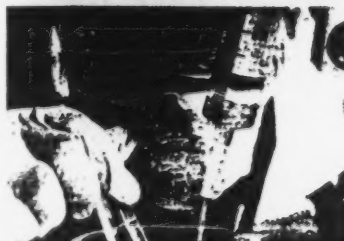
1 Consumers

(people with disabilities and their families) affiliated with independent living organizations,



2 Stakeholder Groups

Representatives of stakeholder groups providing services or information to people with disabilities and their families, and



3 Researchers

funded by grants and contracts through the National Institute for Disability and Rehabilitation Research (NIDRR).

continued on page 2

continued on page 2

NCDDR Completes Pilot Phase*continued from page 1*

to develop a collegial relationship with grantees to help support the growing demand for broader and more effective dissemination and utilization outcomes. NIDRR grantees have assumed new dissemination-related responsibilities such as developing and maintaining rapidly increasing numbers of World Wide Web sites.

Continuation of NCDDR Work

The NCDDR is pleased to announce that it has been awarded a new grant from NIDRR that will continue its work into 2004. Past services and resources will be maintained in the new NCDDR scope-of-work and new activities will be added. Some of these new additions include:

- monitor and report on the state-of-the art in disability research dissemination and utilization;
- expansion of World Wide Web informational resources highlighting and describing research outcomes produced by NIDRR grantees;
- develop information and provide assistance in conducting effective outreach to diverse and emerging audiences;
- provide information and assistance related to producing high quality alternate formats of research outcome information;
- facilitate identification and use of effective dissemination strategies conducted by NIDRR's grantees;
- provide onsite and offsite technical assistance to NIDRR's grantees in planning, evaluating, and improving dissemination and utilization outcomes; and
- expand electronic and in-person networking opportunities for NIDRR-sponsored researchers and grantees.

The NCDDR staff will continue to:

- produce and distribute issues of *The Research Exchange*;
- develop and distribute original documents highlighting the accomplishments and state-of-the-art research outcomes produced by NIDRR research grantees;
- expand the availability of Spanish language versions of disability research information;
- maintain the toll-free access to NCDDR staff and materials;
- maintain and refine the NCDDR website, <<http://www.ncddr.org>>; and
- provide assistance and guidance regarding innovative dissemination and utilization strategies that may meet NIDRR grantees' needs.

The NCDDR staff look forward to continuing the significant advancements that have been made in the dissemination and utilization of NIDRR-sponsored research. As the potential for more effective dissemination practices expand in the next millennium, the NCDDR will work to facilitate awareness and utilization opportunities for all NIDRR grantees.

*John D. Westbrook, Ph.D.
Director, NCDDR*

How Do NIDRR Grantees Disseminate Information?*continued from page 1*

The first (consumer) phase involved independent living organizations, including Title VII-funded Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs) and other independent living programs. A total of 1,238 consumers affiliated with 277 independent living organizations responded. Results were presented in *The Research Exchange*, Vol. 2, No. 4 (NCDDR, 1997a) and the *Report of NCDDR Consumer Survey* (NCDDR, 1997b).

Phase 2 of the study surveyed various stakeholder groups in order to learn how their organizations prefer to receive information and how they typically get information to their audiences. Of 1,789 surveys sent, 851 completed surveys were returned from representatives of a number of constituencies. These included rehabilitation researchers; administrators of independent living organizations and medical rehabilitation facilities; directors of Client Assistance Programs/Protection and Advocacy Agencies; State Directors of Special Education; Federal and State legislators/aides; members of Committees on Employment of People with Disabilities, and disability media representatives. Results were presented in *The Research Exchange*, Vol. 3, No. 2 (NCDDR, 1998a) and the *Report of NCDDR Stakeholder Survey* (NCDDR, 1998b).

The Research Exchange, a newsletter to promote the effective dissemination and utilization of disability research outcomes, is published quarterly by the National Center for the Dissemination of Disability Research (NCDDR) which is operated by the Southwest Educational Development Laboratory (SEDL). Neither SEDL nor the NCDDR discriminate on the basis of age, sex, race, color, creed, religion, national origin, sexual orientation, marital or veteran status, or the presence of a disability. SEDL is an Equal Employment Opportunity/Affirmative Action Employer and is committed to affording equal employment opportunities for all individuals in all employment matters. The contents of this newsletter were developed under a grant (#H133D50016) of \$608,100 from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education (ED). However, these contents do not necessarily represent the policy of SEDL, NIDRR, or the ED; do not assume endorsement by the Federal Government.

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<<http://www.ncddr.org/researchexchange/>>

***The Research Exchange* is available in alternate formats upon request.**

John Westbrook, Director
Lin Harris, Information Assistant
John Middleton, Web Administrator
Joann Starks, Program Associate
Woody Woolcock, Program Specialist
Jane Thurmond, Graphic Design

The data gathered in the first two phases of the study were used to develop instrumentation for the final survey of NIDRR grantees. The focus in this final phase was to identify the dissemination practices of grantees, whose audiences include consumers as well as other stakeholder groups. The responses of NIDRR grantees were also compared with those of consumers and stakeholders to identify areas of consistency or gaps. In addition, grantee responses will be compared with data from an initial survey of grantees conducted in 1996 and reported in *The Research Exchange*, Vol. 1, No. 3.

Procedures

The survey was conducted in late 1998 and early 1999 through telephone interviews with the NIDRR projects' Principal Investigator or a designated Contact Person. In some cases, respondents requested that the questionnaire be sent by surface mail, fax, or electronic mail. A letter and copy of the questionnaire were sent to the 18 grantees NCDDR staff could not contact by telephone.

A total of 309 projects funded by NIDRR during FY 1999 were included in this survey. The projects in 13 program areas were generally funded from 6 months (Small Business Innovative Research) to 60 months (Rehabilitation Research Engineering Centers, Rehabilitation Research and Training Centers, and others). The numbers of projects in each program area are presented in Table 1.

The survey had three parts. The first part updated contact information in the NCDDR database such as contact names, addresses, and telephone numbers. This information is not included in the survey report. The second part was a series of questions about how the project preferred to receive information from the NCDDR, and the possible modes and formats the project could use to disseminate their project's information. The last part was more open-ended and asked grantees about outreach activities as well as their need for technical assistance from the NCDDR. After completing the survey, respondents were asked if they had information to share with the NCDDR about special recognition for their NIDRR project or its staff, or any activities that could be entered in the NIDRR projects' calendar on the NCDDR Web site.

The survey questions are presented on pages 4 and 5. Questions 1–11 refer to dissemination preferences and practices. Questions 12 and 13 refer to outreach strategies. Questions 14 and 15 focus on technical assistance needs of grantees.

Findings and Implications

Surveys were completed for 294, or 95 percent, of the grantees contacted in late 1998 and early 1999. Table 1 shows the rate of responses from each NIDRR program area.

TABLE 1:
Response Rate by NIDRR Program Area (Percent)

Program Area	No. Grantees	No. Responses	Response Rate (%)
ADA Technical Assistance Programs	12	12	100
Advanced Rehabilitation Research Training Projects	8	8	100
Disability and Rehabilitation Research Projects	37	36	97
Fellowships	10	10	100
Field-Initiated Projects	80	77	96
Model Spinal Cord Injury Systems	18	18	100
Rehabilitation Research and Training Centers	42	41	98
Rehabilitation Research Engineering Centers	17	16	94
Small Business Innovative Research—Phase I	13	10	77
Small Business Innovative Research—Phase II	6	6	100
State Technology Assistance Programs	59	54	92
Utilization Projects	5	4	80
Contracts	2	2	100
TOTAL FOR ALL PROGRAMS	309	294	95

NIDRR Grantee Survey Questions

1. Is regular-sized print a workable and preferred format for you to receive **day-to-day communication** from the NCDDR?
- ☐ Yes ☐ No
2. If regular-sized print is not your preferred format, please indicate the format that you would prefer for day-to-day communications.
- ☐ Large print ☐ Braille
☐ Computer disk ☐ Audio tape
- (check format)
- ☐ Mac/Text only ☐ Mac/MS Word ☐ Mac/Word Perfect
☐ DOS/Text only ☐ DOS/MS Word ☐ DOS/Word Perfect
☐ ASCII
3. Would you prefer to receive day-to-day communication by **US Mail**?
- ☐ Yes ☐ No
4. If the US Mail is not your preferred mode of distribution for day-to-day communication, please indicate the mode that you would prefer.
- ☐ Fax ☐ E-mail ☐ Other (please describe)
5. Is regular-sized print a workable and preferred format for you to receive **materials and products** from the NCDDR? (such as a quarterly newsletter, information guides, or other products)
- ☐ Yes ☐ No
6. If regular-sized print is not your preferred format, please indicate the format that you would prefer for other materials and products.
- ☐ Large print ☐ Braille
☐ Computer disk ☐ Audio tape
- (check format)
- ☐ Mac/Text only ☐ Mac/MS Word ☐ Mac/Word Perfect
☐ DOS/Text only ☐ DOS/MS Word ☐ DOS/Word Perfect
☐ ASCII
7. Would you prefer to receive other materials and products by **US Mail**?
- ☐ Yes ☐ No
8. If the US Mail is not your preferred mode of distribution for other materials and products, please indicate the mode that you would prefer.
- ☐ Fax ☐ E-mail ☐ Other (please describe)

9. What formats do you use in disseminating information from your project to your target audiences?

For each item listed, please respond if your project has the capability to provide information in that format, if requested. Answer YES if your project does provide or has the capability to provide information using the format listed, even if you may not actually have done so. If YES, please identify if the format is FREQUENTLY USED.

- | | | |
|--------------------------------------|---|---|
| ☐ Large print | ☐ Visual/graphic/video | ☐ Descriptive video |
| ☐ Braille | ☐ Opened caption video | ☐ Electronic/computer file or disk |
| ☐ Audio/oral | ☐ Closed caption video | ☐ Other language |

10. What modes of distribution are available for disseminating information materials from your project to your target audiences?

For each item listed, please tell if your project has the capability and access to resources to provide information in that mode, if requested. Answer YES if your project does provide or could provide information using the mode listed, even if you may not actually have done so. Answer FUTURE if your project could not currently provide information in that mode, but has discussed plans to make such alternatives available. Answer FUTURE even if such plans are very tentative or not yet fully defined.

- | | | |
|---|-------------------------------------|--|
| ☐ US Mail | ☐ Audio Tape | ☐ Internet/WWW |
| ☐ Text Telephone | ☐ Video Tape | ☐ Computer Disk |
| ☐ Fax | ☐ E-mail | ☐ CD-ROM |

11. How does your organization usually get information to consumers (people with disabilities and their families)?

Answer YES if your project does provide, plans to provide or in the past year has provided information to consumers in this way. If YES, please identify if the format is FREQUENTLY USED.

- | | | |
|---|--|--|
| ☐ Personal communication | ☐ Computer online (WWW, Internet) | ☐ Training Sessions/classes/workshops |
| ☐ Newsletters | ☐ Telephone/Information line | ☐ Library/Information holdings |
| ☐ Information mail outs | ☐ Telephone/Information line | ☐ Reports |
| ☐ Electronic mail | ☐ Fax | ☐ Other |

12. Has your NIDRR-funded project used (or do you have plans to use) computer-based outreach strategies (such as electronic mail, listservs, World Wide Web pages, CD-ROM) to share information with:

- ☐ consumers with disabilities and their families
- ☐ other researchers
- ☐ service providers
- ☐ other target audiences

13. What other outreach strategies do you find most effective for disseminating relevant information to: (please specify)

- ☐ consumers with disabilities and their families
- ☐ other researchers
- ☐ service providers
- ☐ other target audiences

14. Do you perceive a need for technical assistance on planning or implementing outreach strategies, and if so, in what areas?

- ☐ No
- ☐ Yes (if yes, please give examples)

15. Please identify any other ways the NCDDR could provide assistance to your NIDRR-funded project(s).



How Do NIDRR Grantees Disseminate Information?

continued from page 3

TABLE 2:
Formats and Modes Preferred by Grantees for Receiving Day-to-Day Communication from the NCDDR

Grantees N=294		
Format	Number	Percent
Regular Print	282	95.9
Large print	3	1.0
Braille	0	0.0
Audio Tape	0	0.0
Mac File/disk	0	0.0
MAC-text	0	0.0
MAC-MSWord	0	0.0
MAC-WP	0	0.0
PC File/disk	2	0.7
DOS-text	0	0.0
DOS-MSWord	1	0.3
DOS-WP	0	0.0
ASCII	0	0.0
Mode of Distribution		
US Mail	103	35.0
Fax	26	8.8
E-mail	165	56.1
Other	0	0.0

TABLE 3:
Formats and Modes Preferred by Grantees for Receiving Materials and Products from the NCDDR

Grantees N=294		
Format	Number	Percent
Regular Print	278	94.6
Large print	3	1.0
Braille	0	0.0
Audio Tape	0	0.0
Mac File/disk	0	0.0
MAC-text	0	0.0
MAC-MSWord	0	0.0
MAC-WP	0	0.0
PC File/disk	9	3.1
DOS-text	0	0.0
DOS-MSWord	2	0.7
DOS-WP	1	0.3
ASCII	1	0.3
Mode of Distribution		
US Mail	231	78.6
Fax	3	1.0
E-mail	61	20.7
Other	0	0.0

Formats and Modes Preferred by Grantees

Tables 2 and 3 show the responses for Questions 1-8 about the formats and modes that grantees prefer for receiving information from the NCDDR. About 96 percent of respondents preferred to receive **Day-to-Day Communication** in a *Regular Print* format, 1 percent identified *Large Print* and another 1 percent preferred information in *Electronic Disk* format. *Electronic mail* was the delivery mode most preferred, and was identified by 56 percent of respondents. *US Mail* was the preferred mode for 35 percent of respondents, and 9 percent identified *fax* as a preferred mode.

Few changes were seen in preferred formats to receive **Materials and Products**. About 95 percent of respondents preferred *Regular Print*, 1 percent selected *Large Print* and about 3 percent preferred information in *Electronic Disk* format. More changes were found for delivery modes: *US Mail* was the preferred mode for 79 percent of respondents, *Electronic Mail* was preferred by 21 percent, and about 1 percent identified *Fax*.

These data provide some indication of the impact of technology on the communication preferences of NIDRR grantees since the initial NIDRR grantee survey was conducted in 1996 (see *The Research Exchange*, Vol. 1, No. 3). Little change was observed in the preference of formats. Regular print was preferred by 98 percent of respondents in 1996 and by 96 percent in 1999.

In comparing the 1996 and 1999 surveys, there was an increase in preference for electronic communication as a mode of distribution. US Mail was preferred by 69 percent of grantees in 1996, but decreased to 35 percent in 1999. In contrast, 29 percent of grantees preferred E-mail in 1996 compared with 56 percent in 1999. The two surveys showed similar changes in preferred modes for receiving materials and products, with 96 percent preferring US Mail in 1996 and 79 percent in 1999. E-mail preferences for materials and products changed from 4 percent in 1996 to 21 percent in 1999. Fax was the mode preferred for day-to-day communication by 20 percent of grantees in 1996. This decreased to 9 percent in 1999.

Formats and Modes Used for Distribution

Questions 9-11 asked grantees about their capabilities and practices in distributing information to their audiences, including consumers with disabilities. Table 4 shows responses about grantees' use of various formats. Respondents were asked if their project had the capability to produce materials in a format, even if it had not been requested. Grantees were also asked which formats were frequently used when distributing information to their audiences. *Electronic file* was the format identified by the largest percentage of respondents (98 percent). It was also the most frequently used format (43 percent). *Large Print* (96 percent) was the format with the second highest percentage of responses. Over half of the respondents reported having the capability to produce *Audio/oral* formats (87 percent). *Visual/graphic* formats (81 percent), materials in *Other languages* (72 percent), and *Braille*

TABLE 4:
Projects Reporting Capability to Produce Formats and
Formats Frequently Used

Format	Grantees N=294		Frequently Used	
	Number	Percent	Number	Percent
Electronic file	288	98.0	127	43.2
Large print	283	96.3	47	16.0
Audio/oral	255	86.7	48	16.3
Visual/graphic (non-print)	238	81.0	47	16.0
Other language: If YES, which? *	212	72.1	34	11.6
Braille	190	64.6	35	11.9
Opened-caption video	146	49.7	11	3.7
Closed-caption video	139	47.3	5	1.7
Descriptive video	113	38.4	2	0.7

* Spanish=132.

* 27 Other languages=Alaska native, Asian (6), Arabic, ASL, Cambodian, Chamorro (2), Chinese (10), Dutch (5), Filipino (2), French (8), German (11), Greek, Haitian (2), Hmong, Italian (4), Japanese (6), Korean (5), Navajo, Norwegian, Pohnpeian, Polish, Portuguese, Russian (3), Samoan (3), Swedish, Tongan, Vietnamese (3).

(65 percent). None of these formats were frequently used (16 percent or less). Fewer than half of the respondents reported capabilities to produce special video formats (*Opened-caption*, 49 percent; *Closed-caption*, 47 percent; and *Descriptive video*, 38 percent).

A comparison of the 1996 (*The Research Exchange*, Vol. 1, No. 3) and 1999 surveys shows changes resulting from increased computer usage including an increase in capabilities to produce electronic files, from 92 percent in 1996 to 98 percent in 1999, and an increase in capabilities to produce large print from 89 percent to 96 percent. Capabilities to produce Braille documents decreased from 74 percent in 1996 to 65 percent in 1999. In comparing use of the various formats, the percentage of grantees indicating they frequently used the formats in questions 9-11 decreased for every format. Taken in total, these changes perhaps result from alternative formats provided by the Internet and E-mail, plus improvements in such areas as scanner and screen reader technology and affordability.

Table 5 reports grantee responses about their use and planned use of modes of distribution. *US Mail* (100 percent), *Fax* (99 percent), *Electronic mail* (99 percent) and *computer disk* (97 percent) were modes used by nearly all grantees. Other modes reported by a large number of respondents included *Internet* (89 percent), *Audio tape* (80 percent), *Text telephone* (70 percent), and *Video tape* (69 percent). The only mode reported by less than half of the grantees was *CD-ROM* (42 percent). Nearly 24 percent of grantees reported plans to use *CD-ROM* as a distribution mode in the future.

TABLE 5:
Current and Projected Use of Modes of Distribution

Mode	Grantees N=294		Planned for Future	
	Number	Percent	Number	Percent
US Mail	293	99.7	—	—
Fax	290	98.6	—	—
E-mail	290	98.6	1	0.3
Computer disk	285	96.9	6	2.0
Internet/World Wide Web	261	88.8	26	8.8
Audio tape	237	80.6	14	4.8
Text Telephone	207	70.4	10	3.4
Video tape	202	68.7	24	8.2
CD-ROM	123	41.8	69	23.5

Interesting contrasts occurred between grantees' use of the Internet/World Wide Web in the 1996 survey where 51 percent of grantees reported current usage, and 33 percent projected future usage, compared with 1999 survey data indicating 89 percent usage and 9 percent projected future usage. These data, coupled with an increase in E-mail usage from 91 to 99 percent, indicate an increasing reliance on the Internet as a favored distribution mode.

Table 6 reports specific strategies used by grantees to get information to consumers (persons with disabilities and their families). This question was asked of stakeholders in previous survey activities and their responses were compared to those of grantees. All strategies were used by over 60 percent of grantees, with *Personal communication* (96 percent) receiving the highest percentage of responses.

TABLE 6:
How grantees get information to consumers

Strategies	Grantees N=294		Frequently Used	
	Number	Percent	Number	Percent
Personal communication	283	96.3	186	63.3
Computer online (Internet, WWW)	258	87.8	103	35.0
Training/classes/ workshops	257	87.4	117	39.8
Electronic mail	255	86.7	101	34.4
Fax	254	86.4	79	26.9
Information mail outs	240	81.6	93	31.6
Reports	229	77.9	54	18.4
Telephone/ information line	202	68.7	96	32.7
Newsletters	196	66.7	93	31.6
Library/ information holdings	183	62.2	50	17.0
Other (please describe)	77	26.2	16	5.4

How Do NIDRR Grantees Disseminate Information?

continued from page 7

The category *Other* was chosen by 26 percent of respondents. Other strategies identified included:

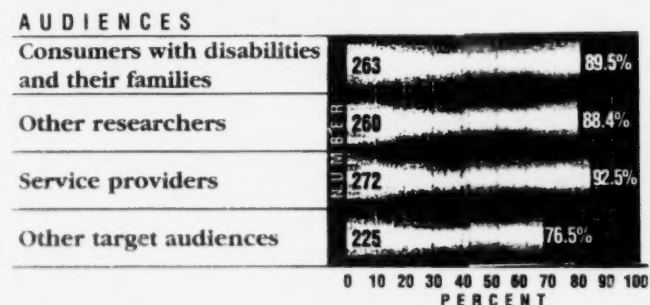
- Conference exhibits, presentations (9)
- Community events, town meetings (9)
- Support groups, forums, focus groups, peer mentoring (8)
- Popular publications, magazines, newspapers (7)
- Distance learning, listserv, video conference (7)
- Database of resources (6)
- Press releases, public service announcements (6)
- Advisory board (5)
- CD-ROM materials (5)
- TV, public TV (4)
- Consumer videos (4)
- Chat rooms (4)
- Audio conference, referrals, brochures, mobile van, journal articles, posters

In comparing the data on Table 6 with similar data from representatives of stakeholder groups reported in *The Research Exchange*, Vol. 3, No. 2, about 88 percent of grantees used the Internet and electronic mail to get information to consumers, whereas approximately 24 percent of stakeholder groups used these modes. This latter percentage is consistent with the percentage of consumers who used the Internet as a source of information (27 percent) as reported in *The Research Exchange*, Vol. 2, No. 4. This disparity may be explained by the need for stakeholder groups to communicate with consumers as their primary audience, while research organizations must communicate with a variety of professional and consumer audiences. However, it also indicates a continued need to use a variety of communication modes to provide consumers and stakeholders with information.

Outreach Strategies

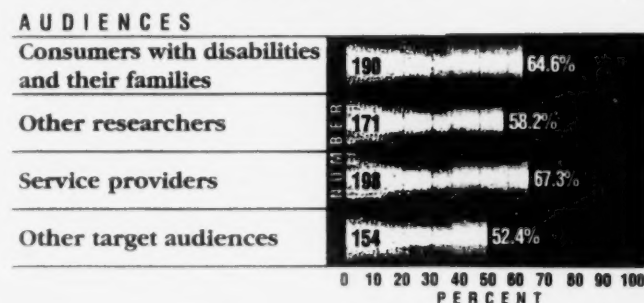
Grantees were asked if their NIDRR-funded project used (or had plans to use) computer-based outreach strategies such as electronic mail, listservs, World Wide Web pages, and CD-ROM formats for sharing information. There were four groups identified as recipients of grantee computer-based outreach: Consumers with disabilities and their families, Other researchers, Service providers, and Other target audiences. Grantees reported high use of computer-based strategies with all groups, ranging from 77 percent (Other target audiences) to 93 percent (Service providers). Figure 1. reports these responses.

FIGURE 1:
Percentage of Grantees Reporting Use of
Computer-based Outreach Strategies



Grantees were also asked about use of other effective outreach strategies with the same groups (see Figure 2.). Over half the respondents reported use of such strategies, from 52.4 (Other target audiences) to 67.3 percent (Service providers).

FIGURE 2:
Percentage of Grantees Reporting Use of
Other Effective Outreach Strategies



Some of the effective strategies identified include:

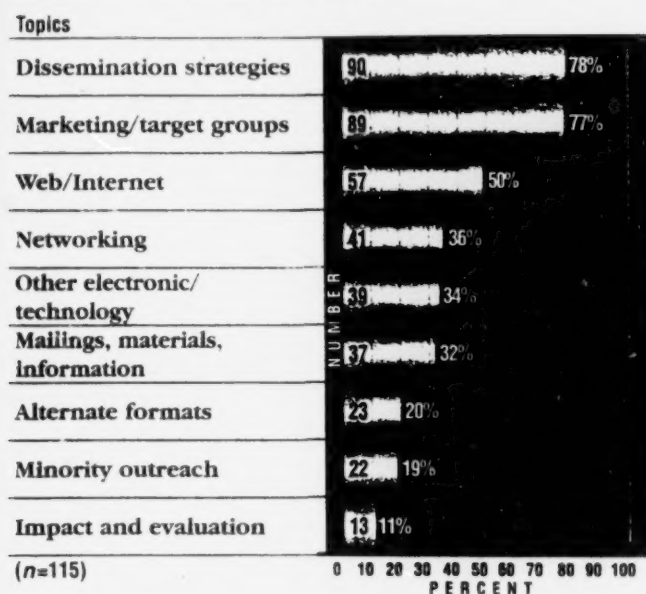
- many computer and technology-based strategies such as electronic mail, distance learning, Web-based materials (66)
- conference presentations (60)
- special training sessions/workshops (45)
- newsletters, brochures, other publications (38)
- journals/trade journals (19)
- training the trainer (4)
- direct in-service (3)
- audio tapes, video tapes, advisory groups, television and radio, exhibits, toll-free number, teleconferences, networking with industry and others

Grantee Technical Assistance Needs

In the last part of the survey, NIDRR grantees were asked about their need for technical assistance (TA) in planning and implementing outreach strategies, TA in other areas, or need for any other type of assistance. Figure 3. identifies specific areas of TA requests. Responses included a total of 115 grantees who requested TA in planning and implementing outreach strategies and/or requested other TA or assistance.

BEST COPY AVAILABLE

FIGURE 3:
Number and Percent of Technical Assistance Requests, by Topics



These data provide valuable cues to the NCDDR for prioritizing future informational and technical assistance activities. NCDDR informational sources, such as *The Research Exchange*, have consistently provided information about dissemination strategies, recently emphasizing cultural diversity and publishing in the popular, disability, and professional media. Future volumes will continue this emphasis while extending the NCDDR's focus to include researching target markets and developing marketing strategies, as well as a continuous updating of information about electronic communications and technology. The NCDDR will continue to focus on how service providers and consumers can get research information they can use. This will include electronic and interpersonal networking strategies, particularly in working with diverse consumer markets for research information.

Conclusion

It is interesting to observe the evolution of the NIDRR grantees' communication formats, modes, and strategies over time, particularly from the initial grantee survey in early 1996 to the recent survey in early 1999. In 1996, 51 percent of grantees reported use of the Internet/World Wide Web and 33 percent projected future usage. The 1999 survey reveals that grantees exceeded those combined percentages (84 percent) with an 89 percent Internet/World Wide Web usage level. With this increased usage, decreases in or stabilized levels for uses of many other modes of communication occurred. It appears that former technological innovations, such as use of computer disks and faxes, are being replaced by new or improved technologies, including World Wide Web information distribution and downloads, and the ability to transmit information and files via E-mail. These data, perhaps, provide a snapshot of widespread changes in the technologies and strategies of information dissemination.

However, enthusiasm about this upsurge in Internet/World Wide Web usage must be dampened by the realization that stakeholders and consumers lag behind researchers in their use of the Internet as a communication mode. Researchers should be careful to continue using a variety of dissemination strategies and modes to ensure that their research information reaches an array of potential users. Although high percentages of grantees use a variety of communication methods, from low tech personal communication to high tech Web sites and CD-ROM materials, there continues to be a need to increase the frequency of dissemination through both traditional and innovative communication methods.

Future innovations are likely to occur in dissemination methods listed under *Other* in Table 6. These include participatory strategies, such as support or focus groups, community events, and town meetings, and through technological innovations in distance learning, video conferencing, listservs, and emerging technologies. Future innovations will bring researchers closer to consumers and stakeholders, resulting in the need to make research information increasingly accessible to and understood by diverse target audiences.

It is apparent that NIDRR grantees are working toward this end and are seeking to go beyond traditional dissemination methods. Grantee requests for technical assistance indicate their interest in diversifying dissemination strategies and developing market research and marketing strategies to extend their efforts beyond distribution of research information to target consumers and stakeholders' information needs. These strategies will include the Internet/World Wide Web and other electronic media as integral components of effective dissemination of research information and knowledge utilization.

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Updated Review of NIDRR Grantees' Web Sites

The use of the World Wide Web as a medium for communication and dissemination by NIDRR grantees has increased dramatically over the four years of the NCDDR pilot project. In mid-1999, approximately 81 percent of grantees ($N=232$) have sites on the Web. Figure 4 shows the increase in the percentage of NIDRR grantees with Web sites from 1996 to 1999. It is important to note that all the funded projects were not the same grantees each year, as some projects were completed while new ones were initiated. However, it is possible to describe the status of NIDRR grantees' Web sites as a group.

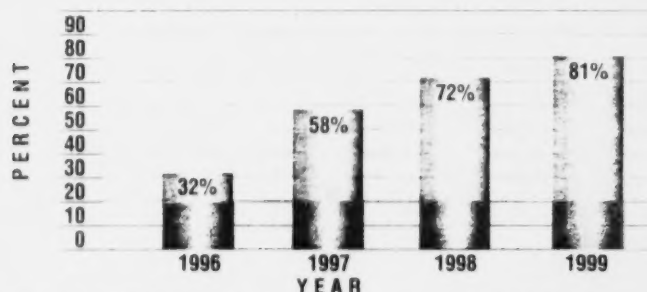


Figure 4. Percentage of NIDRR grantees with Web sites.

NCDDR staff reviewed grantees' Web sites in 1997 (*The Research Exchange*, Volume 3, No. 1) and again in 1998 (*The Research Exchange*, Volume 3, No. 3) to identify common characteristics and look for trends (NCDDR, 1998a, 1998b). These analyses examined 20 characteristics of Web sites, such as:

- use of copyright symbols, disclaimers, acknowledgment of NIDRR, and noting the most recent update of the site;
- links to NIDRR and other NIDRR-funded projects;
- use of text only or text and graphics, as well as, more interactive features such as audio and video, animation, chat rooms, etc.;
- design elements including navigation tools, frames, search engines, and feedback mechanisms such as email or contact forms; and
- accessibility of the Web site to users with disabilities.

Some trends observed from 1997 to 1998 included:

- In 1998, 98 percent of grantees' Web sites used both text and graphics (up from 70 percent in 1997).
- In 1998, nearly three-quarters of the grantees (70 percent) acknowledged NIDRR as the funding agency supporting the project (up from 57 percent in 1997).
- Over half (51 percent) of grantees included one or more links to other NIDRR-funded projects in 1998. This more than doubled, from 23 percent in 1997.
- Nearly one-third (31 percent) of grantees in the 1998 review included a link to NIDRR's home page from their Web site (up from 24 percent in 1997).

Accessibility of Web sites should be an important issue to NIDRR grantees who work to benefit people with disabilities and their families. Grantees that provide information via the World Wide Web should strive to ensure that information is accessible to people with disabilities. *Bobby* software developed by the Center for Applied Special Technology <<http://www.cast.org/bobby/>> rates the accessibility of Web pages as *Bobby Approved* (accessible) or 'not approved' (some elements not accessible).

In the 1998 review, NCDDR staff also looked at several content aspects of grantees' Web sites. All grantees use their Web sites to introduce the organization and/or NIDRR-funded grant project, as well as their products and services. Approximately 56 percent of the NIDRR grantees' sites provided some type of information that could be downloaded or printed, while 5 percent demonstrated a marketing focus that allowed visitors to order information for purchase that was not available directly on the site.

The updating of Web sites ensures that information is current and encourages visitors to return frequently to seek new information. In 1997, an update notice was found on 51 percent of grantees' home pages. The 1998 review found that 41 percent of NIDRR grantees' Web sites provided a notice of the last update to their home pages.

New Review in 1999

A further review of grantee Web sites was conducted in August of 1999. **Accessibility** was reviewed to determine if grantee home pages (not every page in a Web site) were *Bobby Approved*. Since the issue of **copyright** is evolving along with the Web, NCDDR staff looked at home pages to see if a copyright symbol/statement was included. In order to evaluate currency of information, the reviewers looked for evidence of **update** notices on home pages. Finally, site content was examined by identifying if **research results** were available on the Web site, and if so, how current those results might be.

Accessibility. The August, 1999 review examined the accessibility of home pages for people with disabilities, as measured by *Bobby*. Specific NIDRR program areas were examined as well as all grantees as a group. These data are presented in Table 7 for all three review periods. Overall, the percentage of NIDRR grantees' home pages that are accessible has increased each year, and 1999 marks the first time that over half (53 percent) of all grantees' home pages were *Bobby Approved*. Some NIDRR program areas had 100 percent accessible home pages (Utilization, ADA Technical Assistance) while others had none. It is important to note that some of these home pages were constructed by individuals (Fellowships) and others were not developed for use by consumers (Contracts).

TABLE 7

Percentage of NIDRR Grantee Home Pages that are Accessible as Measured by Bobby, by NIDRR Program Areas, 1997-1999

Program Area	1999 N=232	1998 N=213	1997 N=171
ADA Technical Assistance Programs	100	92	39*
Advanced Rehabilitation Research Training Projects ^a	57	33	50
Disability and Rehabilitation Research Projects ^b	41	30	56
Fellowships	0	0	25
Field-Initiated Projects ^c	60	40	20
Model Spinal Cord Injury Systems	29	27	25
Rehabilitation Research and Training Centers	43*	34	31
Rehabilitation Engineering Research Centers	69	38*	56
Small Business Innovative Research	20**	100	50
State Technology Assistance Programs	56	51	37**
Utilization Projects	100	100	67
Contract	0	0	0
TOTAL	53	43	36

* 1 Missing, *Bobby* unable to evaluate

** 2 Missing, *Bobby* unable to evaluate

^a Formerly Research Training Grants, 1997-1998

^b Formerly Research and Demonstration Projects, 1997-1998

^c Formerly Field-Initiated Research Projects, 1997-1998

Care must be taken in drawing conclusions about the percentage of home pages that are *Bobby Approved*. The criteria for approval has changed as the *Bobby* software was revised. The current *Bobby* is version 3.1.1, released on June 9, 1999 (CAST, 1999). The original *Bobby* (no version number) was used in the 1997 review, and *Bobby* 2.01 was used for the 1998 review.

There also were changes in the configuration of some NIDRR program areas between review periods, and each year some project work is completed and new projects are initiated.

Copyright and update. Table 8 reports percentages of grantee Web sites with home pages that:

- included a copyright symbol/notice, and
- included a notice of last update

Data are available for each of the review periods (1997, 1998, and 1999). Less than one-third of grantees used a copyright symbol notice on their Web sites. Approximately half of the Web sites provided an update notice, which was an increase to near 1997 levels after a decrease noted in 1998.

The inclusion of copyright symbols and update notices on home pages does not show consistent trends over the three years, yet it is important to present these data to stress the need to provide stakeholders with protected and current information.

TABLE 8

Percentage of Characteristics Noted Across NIDRR Grantees' Web sites

Characteristics	1999 N=232	1998 N=213	1997 N=171
Copyright Notice included	28	31	21
Update Notice included	50	41	51

The NCDDR also looked at the update notices provided on grantee home pages to determine how long it had been since changes were made to the home page. This review was seen as a rough measure of the extent to which Web site information is kept current, although it was not possible to determine the nature of any changes or updates.

Of the 232 grantee home pages reviewed, 115 (50 percent) included an update notice. Table 9 presents data for 1998 and 1999, showing percentages for time periods of update notices on home pages. Of those home pages that included an update notice, 38 percent had updated the home page within three months prior to the review in August, 1999. This figure is lower than that observed in 1998, but was still the largest proportion of the Web sites that included an update notice. An increase was seen for the two subsequent categories (3-6 months and 6-12 months). The percentage of sites with an update over 12 months prior to the review dropped to 9 percent in 1999.

TABLE 9

Time Periods of Update Notices on NIDRR Grantee Home Pages

Home Pages with Update Notices (n=115, 1999; n=87, 1998)	Percent	
	1999	1998
Update notices less than 3 months old (n=44, 1999)	38	66
Update notices 3 to 6 months old (n=38, 1999)	33	11
Update notices 6 to 12 months old (n=23, 1999)	20	7
Update notices over 12 months old (n=10, 1999)	9	16

Updated Review of NIDRR Grantees' Web Sites

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Research Results on the Web. In 1998, the NCDDR looked at the content of grantees' Web sites by identifying information that could be printed or downloaded for free, or for advertising of materials available for purchase. In this new review, the NCDDR examined each grantees' Web site for the presence of **research results**. These research results included online newsletters, fact sheets, articles, monographs, and reports. The NCDDR did not include marketing brochures, research abstracts, or online catalogue descriptions as examples of online research results.

Table 10 shows that of the 232 Web sites reviewed, 123 (53 percent) provided research results on their Web sites. To determine timeliness of the research results presented on Web sites, the same time periods observed for the update notices were used in this review: less than 3 months, 3-6 months, 6-12 months, and over 12 months. Dates were not found for 17 of the Web sites (14 percent) that provided research results. Of the Web sites presenting research results, the largest time period (27 percent) was results which were included on Web sites from 6 to 12 months before August 1999. The next largest time period represented was over 12 months (24 percent), followed by 3 to 6 months (23 percent). The smallest time period was results less than 3 months, with 12 percent. The NCDDR found that 109, or 47 percent, of the grantees' Web sites did not include research results.

TABLE 10
Time Periods of Research Results on
NIDRR Grantee Web Sites

Web Sites with Research Results (n=123)	Percent 1999
Research results less than 3 months old (n=15)	12
Research results 3 to 6 months old (n=28)	23
Research results 6 to 12 months old (n=33)	27
Research results over 12 months old (n=30)	24
Research results with no date (n=17)	14

Conclusion

The August 1999 review provides some encouraging information about increases in the number of grantees' Web sites and in accessibility for people with disabilities. These increases were seen for grantees as a group, and within particular program areas, over a three year period from 1997 to 1999. Although *Bobby* has become increasingly stringent over its different versions, the accessibility of NIDRR grantee home pages has steadily increased.

The use of update notices also increased to equal the 1997 percentage yet there remains a need for more grantees to provide update notices on their Web sites to help online users determine the currency of information. Given recent concerns about copyright of Web contents (see *The Research Exchange*, Volume 4, Number 3), the relatively level percentages of copyrighted home pages across three years point to the need for grantees to increase copyright usage to protect research information from unauthorized use.

Measures of the time periods of home page update notices and of research results on Web sites provide preliminary indications that information on Web sites is frequently updated. Overall, these data indicate that grantees are developing and improving their Web sites over time, and are increasingly using the Web as a user-friendly and accessible vehicle for disseminating research information.

References

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- NCDDR. (1999). Publishing on the Internet: Possibilities and problems. *The Research Exchange*, 4(3), 11-13. Retrieved September 1, 1999 from the World Wide Web: <<http://www.ncddr.org/researchexchange/v04n03/internet.html>>

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Products Developed by the NCDDR Pilot Project

During its pilot period from 1995 to 1999, the NCDDR produced a number of products aimed at increasing awareness of NIDRR-funded programs and strategies for effective dissemination and utilization. These products provide a solid foundation for future NCDDR activities. Many of these products continue to be available and may be requested by contacting the NCDDR or by accessing the NCDDR Web site at: <http://www.ncddr.org/>.

NIDRR Program Information

The NCDDR maintains current information on its Web site about all programs funded by NIDRR. The NCDDR has produced several posters and a guide to grantees' Web sites to increase awareness of NIDRR-funded research. This awareness was also increased through distribution of press kits detailing NIDRR efforts in employment and rehabilitation engineering.

Doorways to NIDRR Programs and Research

The NCDDR has developed Informational "Doorways" on the NCDDR Web site to introduce stakeholders to NIDRR-funded research programs and to samples of research results produced by NIDRR grantees.



Doorways to NIDRR Programs

NIDRR funds projects that address programs of connected research topics. These programs address a wide variety of issues and policies relevant to the lives of Americans with disabilities and their families. NIDRR Program Doorways currently include:

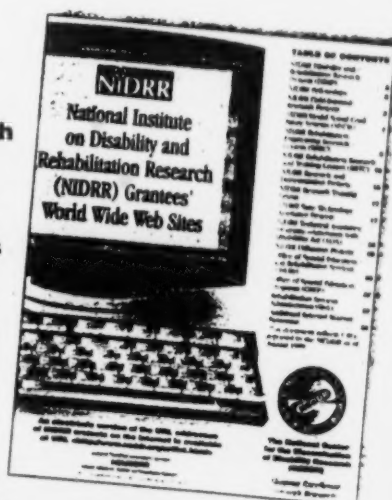
- ◆ Model Spinal Cord Injury Systems (MSCIS)
- ◆ Rehabilitation Engineering Research Centers (RERC)
- ◆ Rehabilitation Research Training Centers (RRTC)
- ◆ Switzer Fellowships
- ◆ Traumatic Brain Injury Model Systems (TBIMS)

<http://www.ncddr.org/nidrrpgmdw/>

National Institute on Disability and Rehabilitation Research (NIDRR) Grantees' World Wide Web Sites

This is a listing of Universal Resource Locator (URL) links that NIDRR grantees have reported to the NCDDR. The online version provides updated links to the Web sites of current NIDRR-funded programs that have an online presence. A printed update will be available in September, 1999.

<http://www.ncddr.org/urlist.html>



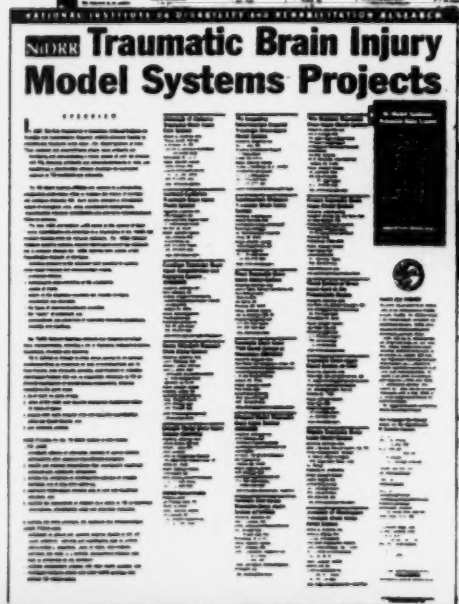
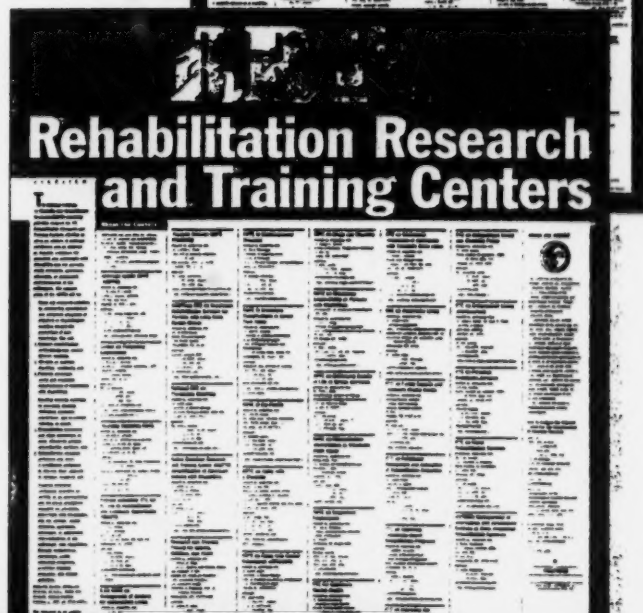
Doorways to Research Topics

The information in these Doorways was developed by NIDRR-funded researchers and is intended for use by the general public, as well as disability researchers, consumers and their families. Each Doorway provides general information about the disability research topic, the results of research carried out by grantees, and links to related information. The Doorways offer text versions of publications, video samples, and audio information. The Doorways to Research Topics that are currently available include:

- ◆ Assistive/Adaptive Technologies
- ◆ Burn Rehabilitation
- ◆ Disability and Health <http://www.ncddr.org/doorways>
- ◆ Emerging Disability
- ◆ Employment
- ◆ Transition to Post-Secondary Schooling for Students with Disabilities
- ◆ Universal Design
- ◆ Women with Disabilities



Products Developed by the NCDDR Pilot Project:
NIDRR Program Information
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Posters for NIDRR Program Areas

Model Spinal Cord Injury Systems (MSCIS) Projects Poster

This reference poster defines the Model Spinal Cord Injury Systems program and provides information about the principal investigator, public contact person, mailing address, telephone (voice and text telephone, if available), fax, email address for designated contact persons, and the World Wide Web address of each current NIDRR-funded MSCIS project.

Rehabilitation Research and Training Centers (RRTC) Poster

This 22X34 full-color poster provides an overview of the NIDRR's RRTC program as well as contact information listed alphabetically by project title for the 40 RRTCs NIDRR funded in 1998. (Out of Print)

Traumatic Brain Injury Model Systems (TBIMS) Projects Poster

This reference poster identifies the current traumatic brain injury model systems grantees and provides information about the principal investigator, public contact person, mailing address, telephone (voice and text telephone, if available), fax, email address for designated contact persons, and the World Wide Web address for each TBIMS project.

Press Releases

Press Release and Press Kit: Centers of Excellence Announced

This press release provides information about NIDRR's initiation of six new Rehabilitation Research and Training Centers on Employment of People with Disabilities. The press kit provided contact and background information on the Centers, NIDRR, the need for employment research, and Rehabilitation Research and Training Centers. (November, 1998) Press Release available:
<<http://www.ncddr.org/news/110498.html>>

Press Release and Press Kit: New Rehabilitation Engineering Research Centers Help Reinvent the Future for Millions of People with Disabilities

This press release provides information about NIDRR's initiation of nine new Rehabilitation Engineering Research Centers. The press kit information included background on NIDRR's RERC program and contact information for the nine new centers. (February, 1999) Press Release available:
<<http://www.ncddr.org/news/99rercpr.html>>

Dissemination and Utilization Resources

The NCDDR has produced an array of publications and tools aimed at improving the effectiveness of dissemination and utilization strategies. Recent additions include the *Guide to Substance Abuse and Disability Resources* and the literature review on *Disability, Diversity, and Dissemination*. These resources provide a base for expanding the NCDDR's efforts in providing information about dissemination and utilization.

Disability, Diversity, and Dissemination: A Review of the Literature on Topics Related to Increasing the Utilization of Rehabilitation Research Outcomes Among Diverse Consumer Groups

This document was prepared to help researchers better understand the interaction of disability, diversity, and dissemination. It provides a theoretical framework examining the concepts of race, ethnicity, and culture, and their influences within the rehabilitation system. It also describes the characteristics of effective 'culturally competent' systems and the impact of attending to diversity in conducting research as well as in dissemination and utilization. A number of organizational, research, and D&U recommendations are provided. (April, 1999)

<http://www.ncddr.org/du/diversity/>

The Dissemination and Utilization of Disability Research: The National Center for the Dissemination of Disability Research Approach

This document discusses dissemination and access issues in effective dissemination, help for NIDRR grantees, benchmarking, and the NCDDR as a dissemination utilization resource. (February 1996)

<http://www.ncddr.org/du/ncddrapproach.html>

Dissemination Self-Inventory: Version One

This dissemination self-inventory is useful to organizations interested in reviewing the relative strengths and weaknesses of planned or ongoing dissemination activities. This self-administered instrument is particularly useful for program managers who may have limited time or who are beginning to implement their dissemination plans. (April, 1997)

<http://www.ncddr.org/dsi/>



General Characteristics of Effective Dissemination and Utilization

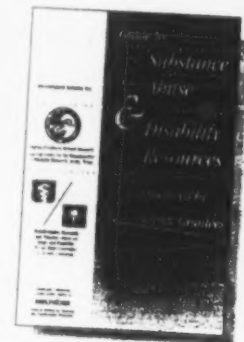
Effective dissemination and utilization strategies are keys to conducting successful program improvement. The strategies suggested in this document are reflective of those found to be effective through both research and field-based experience. (February, 1996)

<http://www.ncddr.org/du/characteristics.html>

Guide to Substance Abuse and Disability Resources Produced by NIDRR Grantees

This guide was developed to assist researchers, professionals, and people with disabilities to locate research-based materials relating to substance abuse and disabilities that were developed by programs funded by NIDRR. (June, 1999)

<http://www.ncddr.org/du/saguide/>



Improving the Links Between Research and Practice: Approaches to the Effective Dissemination of Disability Research Guide to Improving Practice, Number One

This guide discusses in user-friendly language the concept of dissemination for the purpose of knowledge utilization. (July, 1996)

<http://www.ncddr.org/du/guide1.html>

Improving the Usefulness of Disability Research: A Toolbox of Dissemination Strategies Guide to Improving Practice, Number Two

This guide addresses, through user-friendly language, how information can be most effectively disseminated and used by target audiences. (July, 1996)

<http://www.ncddr.org/du/guide2.html>

Multiculturalism and Disability Research: A Summary of Issues and Activities

This document reports on the first meeting of the NCDDR's Multicultural and Disability Research Task Force in Washington, DC on October 21, 1996. It provides a look at the current issues related to multiculturalism. It also reports the task force consensus regarding major multicultural issues and utilization of disability research. (October, 1996)

Dissemination, Utilization, and the NCDDR

This document briefly reviews the history of the dissemination of disability research and its theoretical frameworks and how it relates to the NCDDR approaches, practices, and evaluation activities, as well as the expected implications of increased improved dissemination and utilization. (November, 1995)

<http://www.ncddr.org/du/ncddrdu.html>

Products Developed by the NCDDR Pilot Project:
Dissemination and Utilization Resources
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Report of Field Test Results:

Survey of Consumers with Disabilities

This document reports the field test activity conducted by NCDDR staff to identify the ways consumers (people with disabilities and their families) find disability research information that is useful to them in their daily lives. (October, 1996)

Report of NCDDR Consumer Survey

This report is the result of a survey of consumers and administrators from Centers for Independent Living (CIL) programs around the United States. The volunteers who participated in the survey represent programs in all fifty states. (November, 1997)

Report of NCDDR Stakeholder Survey

This report is the result of survey findings regarding information dissemination and utilization characteristics of disability service

and policymaking stakeholder groups around the United States. The volunteers who participated in the survey represent organizations in all fifty states. The survey represents the first collection of these data at the national level. A mismatch exists in the ways disability services researchers regularly communicate information to consumers and the methods consumers prefer. (August, 1998)

A Review of the Literature on Dissemination and Knowledge Utilization

This review is intended to provide a knowledge base that addresses how disability research results can be more easily accessed and used by those who need them. This review is useful to those conducting research and planning dissemination efforts. Elements of effective dissemination and knowledge utilization are presented as well as ways in which dissemination strategies may be planned and evaluated. (July, 1996)

<<http://www.ncddr.org/du/litreview/>>

PDF Version:

<<http://www.ncddr.org/du/litreview.pdf>>

The Research Exchange Technical Assistance Newsletter

The Research Exchange has achieved a reputation as a high quality source for information about dissemination and utilization strategies, and recognition of NIDRR grantees. This newsletter has presented information on diverse topics of concern to NIDRR grantees and users of NIDRR-funded research. Starting with V1, N2, each issue acknowledges special recognition of NIDRR grantees.

Volume 1, Number 1, Premiere Issue

This premiere issue includes an overview of the NCDDR's information and technical assistance resources, multiculturalism and dissemination, and NCDDR staff introductions. (1995)
<<http://www.ncddr.org/researchexchange/v01n01/>>

Volume 1, Number 2, Availability Versus Accessibility

This issue reviews the need for using alternate formats in dissemination, including: availability and accessibility; dissemination policy; choosing a format; and the NCDDR's World Wide Web site. (1996)
<<http://www.ncddr.org/researchexchange/v01n02/>>

Volume 1, Number 3, Dissemination Patterns of NIDRR Grantees

Information concerning dissemination patterns and characteristics of NIDRR grantees, from the initial grantee survey, is presented. (1996)
<<http://www.ncddr.org/researchexchange/v01n03/>>

Volume 1, Number 4, Literature Review on Dissemination and Utilization of Research Results

This issue highlights some of the information that is contained in three NCDDR publications focusing on dissemination and knowledge utilization theory, approaches, strategies, and effectiveness. The publications are: *A Review of the Literature on Dissemination and Knowledge Utilization*; *Improving the Links between Research and Practice: Approaches to the Effective Dissemination of Disability Research, Guide to Improving Practice, Number One*; and *Improving the Usefulness of Disability Research: A Toolbox of Dissemination Strategies, Guide to Improving Practice, Number Two*. (1996)
<<http://www.ncddr.org/researchexchange/v01n04/>>



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Volume 2, Number 1, Accessible Information on the World Wide Web

Articles include: General Guidelines for Improving Accessibility of World Wide Web Pages; Accessibility Design Considerations and Examples; Annotated WWW Resource List; and NIDRR Project Results Used by Special Olympics International to Evaluate Impact of Sports Program. (1997)

<http://www.ncddr.org/researchexchange/v02n01/>

Volume 2, Number 2, Dissemination Evaluation Strategies and Options

Articles include: You can Evaluate Your Dissemination Efforts; NCDDR Product—Dissemination Self Inventory; and Learning from Business and Industry—Thinking about Your WWW Site: Can It be Evaluated? (1997)

<http://www.ncddr.org/researchexchange/v02n02/>

Volume 2, Number 3, Gateways to NIDRR's Disability Research

This issue highlights the development of NIDRR program WWW doorways on the NCDDR Web site. Also described are the research topic doorways under development by the NCDDR staff. Ways in which the communication power of WWW sites can be assessed is included. (1997)

<http://www.ncddr.org/researchexchange/v02n03/>

Volume 2, Number 4, How Do Consumers Get Information They Can Use?

This issue presents data collected by the NCDDR regarding the ways in which persons with disabilities and their families prefer to receive disability research information for use. The survey process and highlights of the findings are provided. (1997)

<http://www.ncddr.org/researchexchange/v02n04/>

Volume 3, Number 1, Common Characteristics of NIDRR Grantees' Websites

This issue presents information on the common characteristics of NIDRR grantees' Web sites. Also presented are the trends in the dissemination patterns of NIDRR grantees as reported in the *NIDRR Compendium of Products of NIDRR Grantees, 1993-1996*. (1998)

<http://www.ncddr.org/researchexchange/v03n01/>

Volume 3, Number 2, How Do Stakeholders Find and Disseminate Information?

This issue presents the results of the NCDDR's survey of stakeholder groups to learn more about how they obtain and disseminate information. Representatives of rehabilitation researchers, service providers, supporters, and policymakers; information sources participated in the survey. (1998)

<http://www.ncddr.org/researchexchange/v03n02/>

Volume 3, Number 3, Who Needs Web Site Accessibility?

This issue provides helpful information and resources that can guide the user in making their Web site more accessible. An updated "Annotated WWW Resource List" is presented, as well as a new review of NIDRR Grantees' Web sites. (1998)

<http://www.ncddr.org/researchexchange/v03n03/>

**Volume 3, Number 4, Special Employment Issue**

This special issue provides a look at the employment issues currently being faced by Americans with disabilities. NIDRR's new initiative addressing employment-related issues, and the Rehabilitation Research and Training Centers funded to improve employment outcomes for persons with disabilities. (1998)

<http://www.ncddr.org/researchexchange/v03n04/>

Volume 4, Number 1, Disability, Diversity and Dissemination: A Review of the Literature, Part 1—Theoretical Framework

This issue, Part 1 of a review of literature presented in the NCDDR document "Disability, Diversity, and Dissemination: A Review of the Literature on Topics Related to Increasing the Utilization of Rehabilitation Research Outcomes Among Diverse Consumer Groups," provides a theoretical framework for examining the concepts of race, ethnicity, and culture, and their influences within the rehabilitation system. It also includes descriptions of "mainstream" and "ethnic" cultures in the United States. (1999)

<http://www.ncddr.org/researchexchange/v04n01/>

Volume 4, Number 2, Disability, Diversity and Dissemination: A Review of the Literature, Part 2—Applying the Concepts to Research and D&U

This issue, Part 2 of a review of literature focuses on the characteristics of effective systems and how to build relationships within "culturally competent" organizations. The concepts about culture and diversity that were presented in Part 1 (Vol. 4, No. 1) are related to issues in conducting research and issues in dissemination and utilization. The conclusion offers organizational, research, and D&U recommendations. (1999)

<http://www.ncddr.org/researchexchange/v04n02/>

Volume 4, Number 3, Disseminating Research Information in the Disability, Mainstream, and Professional Media

Articles on disability research and the media, developing media relations, and publishing in journals are presented with NIDRR grantees in mind. Issues associated with Internet publishing are discussed for authors who may be interested in both online and journal publishing. (1999)

<http://www.ncddr.org/researchexchange/v04n03/>

Products Developed by the NCDDR Pilot Project:

The Research Exchange

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Volume 4, Number 4, Grantee Survey and Web Site Update

This is the final issue of *The Research Exchange* in NCDDR's pilot phase. It presents the results of a follow-up survey of NIDRR grantees, including comparisons with data from previous surveys. An update of NIDRR grantees' Web sites is presented, as well as a description of NCDDR products developed over the pilot project period. (1999)

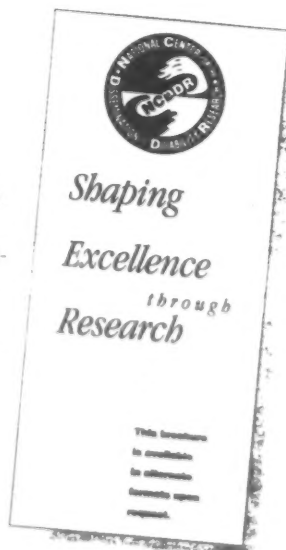
<<http://www.ncddr.org/researchexchange/v04n04/>>

About the NCDDR

The NCDDR provides two brochures to NIDRR grantees and stakeholders interested in the NCDDR's technical assistance services. The brochures contain information about the resources and services available through the NCDDR to improve dissemination and utilization strategies.

Shaping Excellence Through Research

This general brochure describes the way NCDDR works with NIDRR grantees and stakeholders in disability research to expose the barriers to effective dissemination and search for ways to overcome them. It also includes information about technical assistance and training, NCDDR publications, serving underserved groups, and the NCDDR World Wide Web site. (April, 1996)



Technical Assistance Resources

This booklet outlines the technical assistance and training opportunities, both on- and off-site, consultation services, and resources offered by the NCDDR. It also offers a postage paid reply card in addition to other ways to contact the NCDDR to request services. (May, 1996)



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NIDRR Grantee Recognition

The NCDDR congratulates each of the following NIDRR grantees and staff members. All grantees are encouraged to contact the NCDDR with information to share in future issues of *The Research Exchange*.

~

Drs. Rud and Ann Turnbull, Co-Directors of the **RRTC on Policies Affecting Families with Children with Disabilities** at the University of Kansas, were among thirty-six honorees recognized as recipients of the American Association on Mental Retardation (AAMR) *Historic Century Award* during the organization's annual meeting in New Orleans in May, 1999. In addition to the Turnbulls, honorees included President John F. Kennedy, B.F. Skinner, Alfred Binet, Henry Goddard, Gerald Rivera, among others. The honorees were selected based on the selection committee's determination as having made the most significant contributions to the field of mental retardation in the last one hundred years.

NIDRR Participates in Annual Legislative Conference of Congressional Black Caucus Foundation

NIDRR hosted an exhibit in the technology pavilion at the 29th Annual Legislative Conference sponsored by the Congressional Black Caucus Foundation, Inc. The largest African American conference in the nation took place at the Washington Convention Center in Washington, DC, from Wednesday, September 15 to Saturday, September 18, 1999.

Dr. Katherine Seelman, NIDRR Director, participated in the Exhibit Hall Ribbon Cutting at noon on September 15th. Assistant Secretary of OSERS, Judith Heumann, was invited. NIDRR provided printed materials, videos, and demonstrations of items produced by NIDRR grantees. Exhibits were open to the public and up to 30,000 visitors were expected in the Exhibit Hall.

For more information about the Congressional Black Caucus Foundation contact them at 1-800-784-2577 or online at <<http://www.cbconline.org/conference/>>

Dr. Ann Turnbull was also recognized as the 1999 recipient of the *Louise Byrd Graduate Educator Award* at the Doctoral Hooding Ceremony at the University of Kansas School of Education on Saturday, May 22. This award is made annually to a member of the graduate faculty who has demonstrated an unusual concern for the welfare of graduate students.

For further information contact **Anette Lundsgaarde** at (785) 864-7601 or anette@dole.lsi.ukans.edu

Staff members of the **RRTC in Neuromuscular Diseases** at the University of California at Davis received honors from a variety of organizations.

- **William Fowler, M.D.**, former RRTC Director, received the *Deanna Falge Award* presented by the Staff Affirmative Action and Diversity Advisory Committee, University of California at Davis. UC Davis created the award to honor Deanna E. Falge for her commitment to equal opportunity and Affirmative Action as UC Davis' AA/EEO Compliance Officer from 1970 to 1995.

On behalf of all past and present participants in RRTC/NMD projects, **Dr. Fowler** also accepted the *Ninth Annual Affirmative Action and Diversity Award*. This award recognizes UC Davis departments that have made significant contributions to affirmative action/equal employment opportunity and heightened awareness and sensitivity to diversity. Both awards were presented at a luncheon on March 22, 1999 and recipients were honored at a campus celebration, "Soaring to New Heights," on March 25, 1999.

- **Mark Wineinger, M.D.**, received the 1998 Association of Academic Physiatrists *Excellence in Research Writing Award* at the AAP Annual Meeting in Orlando, Florida in February, 1999. **Dr. Wineinger**, who was first author, and his co-authors **Ted Abresch** and **Sandra Davis** from U.C. Davis, and **Greg Carter, M.D.** from the University of Washington, received the award for their paper entitled "Effects of Aging and Voluntary Exercise on the Function of Dystrophic Muscle from mdx Mice" published in the January/February 1998 edition of the *American Journal of Physical Medicine and Rehabilitation*.
- **Robert Emmons, Ph.D.**, and former undergraduate research assistants **Chi Cheung** and **Keivan Tehrani** were awarded a *Templeton Foundation 1998 Exemplary Papers Award* for a research article entitled "Assessing Spirituality Through Personal Goals: Implications for Research on Religion and Subjective Wellbeing," published in *Social Indicators Research*, 45, 391-422 (1998).

For further information contact **Dr. Kathryn Devereaux**, Director of Training and Information Services, at (530) 752-9270.

Dr. Frederick E. Menz, Director of Research and Associate Director of the **RRTC on Improving Community-Based Rehabilitation Programs**, received the *Outstanding Researcher of the Year* award from the National Council on Rehabilitation Education. He was recognized for his accomplishments in advancing the rehabilitation counseling profession through research and training activities of national significance. The award was given in Washington, D.C. in June, 1998. For further information contact **Julie Larson** at (715) 232-2236 or larsonj@uwstout.edu

Staff of the **RRTC on Aging with Mental Retardation (RRTCAMR)** received awards at the Annual Convention of the American Association on Mental Retardation (AAMR) held in New Orleans in May, 1999.

- **Tamar Heller, Ph.D.**, Principal Investigator and Director of RRTCAMR, was elected President of the Gerontology Division of the American Association on Mental Retardation, 1998-2000.
- **David Braddock, Ph.D.**, Co-Principal Investigator, was named *Distinguished Lecturer* for the Convention and received the *Career Research Award*, an international award presented to nine biomedical and social science researchers since 1980.
- **Harvey Sterns, Ph.D.**, Project Director and Professor of Psychology at the University of Akron, received the *Ruth Roberts Memorial Award* from the Gerontology Division of the AAMR for his contributions to the field of aging with mental retardation.

For further information contact **Alan Factor, Ph.D.**, Associate Director for Training and Dissemination, at (312) 413-1520 or afactor@uic.edu

Kenneth E. Galea'i, Ph.D., Co-Director and Coordinator of Research at the **RRTC of the Pacific**, was appointed by the U.S. Secretary of Commerce to the *Race and Ethnicity Advisory Council to the US Census* and serves as a member of the *Pacific Islander Subcommittee on Census 2000*. For further information contact **Fred McFarlane, Ph.D.**, Center Director, at (619) 594-6115/4220 or fmcfarla@mail.sdsu.edu

Robert Blum, M.D., Ph.D., Principal Investigator at the **Research and Training Project for Infants, Children, and Youth**, was the recipient of the 1998 *Herbert Needleman Award* from the American Public Health Association for "Outstanding Contributions in Research and Courageous Advocacy for Child and Adolescent Health." The award was presented at the annual meeting of the American Public Health Association, November 1998, in Washington, D.C. For further information contact **Marty Smith** at (612) 626-3014 or martys@tc.umn.edu

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NIDRR Grantee Recognition

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The **RRTC on Drugs and Disability** and staff members received the following honors.

- In January 1999 the RRTC and its parent organization, Substance Abuse and Disability Issues (SARDI), were awarded the *1998 Ohio Exemplary Prevention Award* by the Ohio Department of Alcoholism and Drug Addiction Services (ODADAS) for the "PALS Project—Adapting Prevention Education for Youth with Disabilities."
- **Dennis Moore, Ed.D.**, RRTC Director, was recognized for his efforts as *Chair* and primary conceptualizer of the recently released Treatment Intervention Protocol monograph #29 entitled "Substance Use Disorder Treatment for People with Physical and Cognitive Disabilities." This recognition was made at a press conference conducted by the Substance Abuse and Mental Health Services Administration (SAMHSA) on January 12, 1999 at the National Press Club in Washington, D.C.
- **Eileen Wolkstein, Ph.D.**, RRTC Training Director, was appointed to the National Advisory Board for the Addiction Technology Transfer Centers (ATTC), sponsored by SAMHSA. The ATTCs are responsible for a national training agenda for the addictions field. **Dr. Wolkstein** is on faculty in the Health Studies Department at New York University.

For further information contact **Dr. Dennis Moore** at (937) 259-1384 or dcmoore@desire.wright.edu

NCDDR to Begin New Work

This issue of *The Research Exchange* marks the culmination of the NCDDR's pilot project, providing updated information about innovations that NIDRR grantees are achieving in developing and disseminating research information. In its new project, the NCDDR will continue to assess these innovations and assist grantees in their dissemination efforts, as well as helping stakeholders and consumers locate research information in online and traditional media. More importantly, as evidenced by the NCDDR product list in this issue, the NCDDR will continue to work with grantees in developing and refining dissemination strategies that result in the utilization of research information. Thus, the NCDDR will continue to develop new materials and methods to help grantees, stakeholders, and consumers to develop and access the research information they need to produce lasting change and improvements in the lives of people with disabilities. The staff of the NCDDR look forward to the challenges and rewards of assisting NIDRR grantees, stakeholders, and consumers during the coming five years.

How To Contact The National Center For The Dissemination Of Disability Research



Call Us

1-800-266-1832 or 512-476-6861 V/TT
8 A.M.—NOON and 1 P.M.—5 P.M. C.T. Mon.—Fri.
(except holidays) or record
a message 24 hr./day



Explore Our Web Site

<http://www.ncddr.org/>

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admin@ncddr.org



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